An Exploration of the Influence of Stigma and Trauma in the Illness Representations of those Veterans who Decided to Initiate Treatment for Hepatitis C Virus

By

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A Dissertation

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Dedication

This work is dedicated to the family, friends, and colleagues who believed in me, encouraged me, and stuck with me as I tackled the greatest intellectual and creative challenge of my life. Words cannot describe what you all mean to me. From the bottom of my heart, I thank you.

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Abstract

Hepatitis C Virus infection (HCV) is a blood-borne illness that presents a long-term risk for cirrhosis and hepatocellular carcinoma, despite being otherwise largely asymptomatic. Veterans in the United States (U.S.) are disproportionately affected by HCV and contend with challenges that may complicate treatment initiation. These challenges include stigma, which has been recognized as a barrier to care, as well as symptomatic responses to trauma, which may discourage treatment seeking. The following dissertation report presents three manuscripts. The first, describes the application of the Common-Sense Model (CSM) to veterans with HCV. The second presents an argument for the utilization of theoretical frameworks in the qualitative paradigm. Finally, the third presents the findings of the dissertation study. This qualitative study sought to understand how veterans who contended with stigma and trauma, decided to initiate treatment with current oral direct-acting antiviral medications (DAAs). The CSM provided a theoretical framework to understand how illness perceptions or illness representations influenced the decision to initiate treatment. The finding of this study enriched the understanding of how veterans contending with stigma and trauma, initiated treatment for HCV, but suggest the need for further investigation. This is particularly important in this time when tolerable and effective treatment is available.
Chapter 1: Introduction

Hepatitis C Virus (HCV) is a blood-borne pathogen that can be asymptomatic for years but is associated with cirrhosis and hepatocellular carcinoma in the long-term (Centers for Disease Control and Prevention [CDC], 2020). Recent developments in oral direct-acting antiviral medications (DAAs) have brought about realistic options for a cure (Moon, Green, Berry, & Ioannou, 2017). These DAAs include the oral combination of Glecaprevir and Pibrentasvir, which features an SVR rate ranging from 83% to 100% and is associated with tolerable side-effects for most patients (Kwo et al., 2017). With the ongoing opioid epidemic (Jones, Christensen, & Gladden, 2017), the incidence of HCV has increased accordingly because of its association with injection drug use (Zibbel et al., 2018). This presents an impetus to gain a greater understanding of how affected populations, such as veterans, choose to initiate treatment.

Of the approximately 5.7 million veterans who received outpatient care through the Veteran’s Affairs (VA) health system in 2015, HCV prevalence was 3.1% (approximately 177,000 individuals; Noska et al., 2017). This is compared to the approximate 1% prevalence in the total United States (U.S.) population between 2013 and 2016 (Hofmeister et al., 2019). More than 90% of veterans receiving care within the VA are men (VA 2020c), so it is understandable that most of those with HCV at the VA are men (96.5% men vs 3.5% women; Noska et al., 2017). Veterans born between the years 1945 and 1965 have the highest prevalence (10.3% among men, and 4.7% among women: compared to 1.2% and 0.7% prevalence among men and women respectively born after 1965; Backus, Belperio, Loomis, & Mole, 2014). Black or African American veterans have the highest prevalence (11.8%), compared to Latinx veterans (6.4%) and white veterans (4.8%; Backus et al., 2014). Homeless veterans have a prevalence of HCV more than four times that of non-homeless veterans (12.1% vs. 2.7%; Noska et al., 2017).
Findings from previous qualitative research among veterans treated for HCV suggest they appreciate that HCV is a potentially fatal illness (Clark & Gifford, 2015, Phillips & Barnes, 2016). Moreover, findings suggest that some veterans believe that HCV is controllable through medication and personal actions (Clark & Gifford, 2015; Phillips & Barnes, 2016), and that they are hopeful for a cure (Skolnik et al., 2019). However, because of its association with injection drug use there is considerable stigma attached to HCV infection (Dowsett, Coward, Lorenzetti, McKean, & Clement, 2017). Stigma is understood to be a potential barrier to HCV care and treatment (Miller, McNally, Wallace, & Schlichthorst, 2012; Rogal et al., 2016). In addition, U.S. veterans with HCV contend with trauma (VA, 2014). Symptoms of a traumatic response, including numbness, agitation and resultant avoidance, may discourage seeking care (van der Kolk, 2014). Given that HCV is a frequently asymptomatic illness that often presents with distant consequences, it is possible that treatment may not be seen as a priority for veterans contending with these challenges.

This dissertation sought to address the overall question: “How do veterans, who experience stigma and/or trauma, navigate these challenges to initiate treatment for HCV?” Exploration among veterans who have experienced stigma and trauma, and still initiated treatment, may provide new understanding of how such individuals make decisions to promote health in the face of adversity. The Common-Sense Model (CSM; Leventhal, Phillips, & Burns, 2016) was utilized in this study to frame the understanding of the role of stigma and/or trauma in treatment among veterans with HCV. Nine veterans were recruited for face-to-face, in-depth interviews to discuss their experiences of HCV diagnosis, perceptions of their illness, exposure to stigma or trauma, and how they decided to get treated.

This dissertation report follows the three-manuscript structure required by Northeastern
University. The first manuscript, which serves as Chapter 2 of this report, is entitled *The role of stigma and trauma in Hepatitis C Virus treatment in veterans: Applying the Common-Sense Model*. This article is a discussion of the applicability of the CSM to veterans with HCV (Garvey & Jones, 2019). According to the CSM, one’s memories, sensations and cognitions about an illness comprise a prototype. Such prototypes activate illness representations, which serve as a mental schematic to define a given illness and its treatment in a set period of time (Leventhal et al., 2016). Both prototypes and representations are defined by 1) identity, meaning the signs and symptoms of an illness, 2) cause, meaning the factors that led to an illness, 3) timeline, meaning the chronological course of an illness, 4) consequences, meaning the perceived or expected outcomes of an illness, and, 5) controllability, meaning the capacity to mitigate sickness or maintain health in face of an illness. Representations of a given illness, when matched to an appropriate illness prototype, inform an action plan of how to respond to that illness (Leventhal, Leventhal, & Brelan, 2011; Leventhal et al., 2016). This article includes an in-depth examination of the foundational principles of the CSM. This article also explores the theoretical proposition of the role of stigma and trauma in the formation of prototypes among veterans. It also explores how such prototypes may affect illness representations and action plans concerning treatment initiation. This article was published in the November 2019 issue of *Public Health Nursing* and is included in this report as the original final draft. The final published version is available online through *Public Health Nursing* (https://doi.org/10.1111/phn.12665).

The second manuscript, which serves as Chapter 3 of this report, is entitled *Is there a place for theoretical frameworks in the qualitative paradigm?* This article is a discussion of theoretical frameworks in qualitative research (Garvey & Jones, in review). Theoretical frameworks may be utilized to guide qualitative analyses by suggesting concepts and
relationships among concepts (Miles, Huberman, & Saldaña, 2020). However, there are concerns that the use of a theoretical framework may bias findings or stifle inductive discovery (Corbin & Strauss 2012; Morse, 1992). With these concerns in mind, the goal becomes one of maximizing the utility of a theoretical framework, without distorting the data into an anticipated framework (Corbin & Strauss 2012). This article presents the argument for responsible use of theoretical frameworks in qualitative research, drawing upon examples from the qualitative dissertation study. This article has been submitted to the International Journal of Qualitative Methods and is presently undergoing revision for resubmission.

The third manuscript, which serves as Chapter 4 of this report, is entitled An exploration of the influence of stigma and trauma in the illness representations of those veterans who decided to initiate treatment for Hepatitis C Virus. This article reports on the findings of the qualitative dissertation study. This study entailed in-depth interviews with nine veterans, and subsequent analyses of data utilizing open and axial coding (Corbin & Strauss, 2012). The CSM (Leventhal et al., 2016) provided initial understanding of concepts, a priori categories, and potential relationships between and among concepts. This study sought to address the following research questions (RQs): RQ1: What are the illness representations concerning HCV that led to the action plan of seeking treatment?, RQ2: In what ways are the illness representations of veterans with HCV affected by stigma or trauma? Findings and implications for future research and clinical practice are presented.

It is estimated that as many as 15,000 veterans remain untreated for HCV in the VA system (VA, 2020). Though HCV is now treatable through effective and tolerable oral medication, challenges presented by stigma and trauma may discourage treatment initiation. This dissertation sought to explore how those veterans who experienced stigma and trauma navigated
these challenges to initiate treatment for their HCV infection. The findings of this study have the potential to enrich the understanding of these experiences, with implications for future research exploring the complexities of treatment decisions among veterans with HCV.
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Chapter 2: Manuscript 1

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The Role of Stigma and Trauma in Hepatitis C Virus Treatment in Veterans:

Applying the Common-Sense Model

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Abstract

Hepatitis C Virus (HCV), a bloodborne pathogen capable of causing severe liver disease, disproportionately affects veterans in the United States. While there are antiviral medications to treat HCV, stigma and trauma in this population may lead to avoidance of care. Those veterans who do undergo treatment have certain illness representations about HCV and its treatment. They undergo treatment even while facing stigma and trauma. The Common-Sense Model may be useful in elucidating how such representations, when matched to an appropriate illness prototype, may inform an action plan of how to respond to HCV. An exploration of the illness representations among veterans with HCV, and the effects of stigma and trauma on these representations, may help to explain how they exercise the choice to undergo treatment and may inform interventions to encourage treatment in veterans who have yet to do so.

Keywords: Hepatitis C; veterans, health beliefs, decision making, stigma, psychological trauma, conceptual framework, Common-Sense Model
Prevalence of Hepatitis C Virus (HCV) infection is disproportionately high among veterans in the United States (U.S.; Backus, Belperio, Loomis, & Mole, 2014; Denniston et al., 2014). Infection with HCV can be stigmatizing because injection drug use is a recognized transmission route (Dowsett, Coward, Lorenzetti, MacKean & Clement, 2017). Further, symptoms of trauma are pervasive among veterans with HCV (U.S. Department of Veterans Affairs [VA], 2014). The experiences of stigma and/or trauma could provoke avoidance of HCV treatment. Those veterans who undergo treatment may have perceptions of their illness (Leventhal, Phillips, & Burns, 2016) that facilitate their seeking treatment, notwithstanding exposure to stigma and/or trauma. The Common-Sense Model (CSM; Leventhal et al., 2016), may be useful in examining these perceptions, or illness representations, in veterans who have sought HCV treatment. It may also further the understanding of the effects of stigma and/or trauma on these representations. Such an exploration may help explain how they exercise the choice to undergo treatment.

**Background**

Hepatitis C Virus (HCV) is a blood-borne pathogen capable of causing severe liver disease. The most common route of HCV transmission in the U.S. is injection drug use (Centers for Disease Control and Prevention [CDC], 2018). Most with untreated HCV develop chronic infection and are at increased risk of cirrhosis and hepatocellular carcinoma (HCC; CDC, 2019). Worldwide, there are approximately 71 million persons with chronic HCV (World Health Organization [WHO], 2018), with some 3.5 million in the U.S. (Edlin, Eckhardt, Shu, Holmber, & Swan, 2015). There are nearly 400,000 deaths worldwide each year related to HCV (WHO, 2018).

Antiviral medications are available to treat HCV infection and achieve a sustained-
virologic response (SVR; McHutchison et al., 2009), meaning an undetectable viral load. Achieving SVR has been demonstrated to reduce morbidity and mortality in chronic HCV (Backus et al., 2011; D’Ambrosio et al., 2012). In the past, treatment for HCV was a lengthy and difficult process. A prominent example of the previous era of treatment was injectable Interferon™ and oral Ribavirin™ (INF-RBV), which presented risk for flu-like and psychiatric side-effects, including depression (McHutchison et al., 2009). In addition, these regimens could last up to 48 weeks, and often demonstrated limited efficacy (McHutchison et al., 2009).

Recent advances in antiviral treatment, notably the introduction of direct-acting antiviral drugs (DAA), such as the combination of Sofosbuvir™ and Ledipasvir™, demonstrate increased rates of SVR and reduced treatment length and side-effects (Afdhal et al., 2014). Since the introduction of DAAs, rates of treatment initiation have increased significantly, from under 5,000 HCV cases treated in 2010, to over 30,000 treated in 2015 (Moon, Green, Berry, & Ioannou, 2017). This advancement comes at a time of epidemic increases in injection opioid use in the U.S. (Jones, Christensen, & Gladden, 2017), and concurrent increase in HCV diagnoses (Zibbel et al., 2018). In light of these concerns, it is an opportune time to understand how groups affected by HCV exercise the choice to undergo treatment.

The prevalence of HCV among veterans is estimated at just over 6% (Backus et al., 2014), compared to approximately 1% among the total U.S. population (Denniston et al., 2014). The prevalence of HCV infection is high among male veterans born between 1945 and 1965 (10.3% among male veterans; 4.7% among female veterans; Backus et al., 2014). Women represented less than 3% of HCV diagnoses among veterans at the VA between 2000 and 2013 (Kramer et al., 2017). Black or African American veterans have the highest HCV prevalence of all U.S. veterans (11.8%, vs. 6.4% among Hispanic/Latino veterans, <5% among White veterans;
Backus et al., 2014). Black or African American veterans, along with Latino veterans, are less likely to receive treatment compared to White veterans (Lin et al., 2017). Substance use as well as medical comorbidity have also been associated with a lower likelihood of a veteran receiving a prescription for the new DAA medication (Lin et al., 2017). Additionally, structural factors, such as fragmentation of care and billing issues may affect access to treatment (Tsai et al., 2017). However, these findings do not represent the full spectrum of challenges faced by veterans with HCV as they make the choice to undergo treatment.

Stigma is common among those with HCV infection (Dowsett et al., 2017). The experience of stigma has the potential to discourage seeking care (Weiss, Ramakrishna, & Somma, 2006). Compounding the effects of stigma, many veterans with HCV also have comorbid Posttraumatic Stress Disorder (PTSD; VA, 2014). Intrusive thoughts and hyperarousal resulting from traumatic experiences, and intense efforts to avoid reminders of trauma (van der Kolk, 2014), may further discourage seeking treatment. Veterans may perceive HCV through the lens of such experiences, and thus their efforts to undergo treatment may accordingly be affected by stigma and/or trauma.

The Common-Sense Model (CSM; Leventhal et al., 2016) provides a framework to explore how the illness experience can be filtered through exposure to stigma and/or trauma. Each may become part of an illness prototype, which is defined as a collection of memories consisting of experiences and sensations associated with illness (Leventhal et al., 2016). Such a prototype may affect the formation of future perceptions, or representations of that illness. These representations in turn may lead to an action plan to avoid HCV treatment.

Articles reporting on the CSM and original research on HCV illness perceptions, veterans, antecedents to HCV treatment, and the epidemiology of HCV, were reviewed. These
were indexed in PubMed and Google Scholar. Keywords included, but were not limited to, “Veterans”, “Hepatitis C”, “Stigma”, “Trauma”, “PTSD”, “Common-Sense Model” “Illness Representations”, and “Illness Perceptions”. Literature published within the past ten years (2008 to 2018) was prioritized to capture the most recent literature on these phenomena. Literature outside these guidelines were included if they provided relevant insight into the potential effects of stigma and/or trauma on the prototype and representation formation. These included seminal literature on CSM, as well as news releases and governmental guidelines.

**Stigma**

Stigma is a personal attribute that diminishes a person’s value in the eyes of others and can lead to social exclusion or negative judgement (Goffman, 1986; Weiss et al., 2006). Stigma results from a relationship between a given feature and a discrediting stereotype associated with that feature (Goffman, 1986). Persons may experience stigma related to physical differences and perceived character flaws (such as those attributed to substance use; Goffman, 1986; Weiss et al., 2006). Stigma may also be internalized in the form of self-directed shame (Goffman, 1986). Stigma specific to a given illness is dependent upon stereotypes that result in denigration or isolation, without any justifiable medical basis (Weiss et al., 2006). Individual reactions to being stigmatized vary from efforts to hide the discrediting feature and effectively pass as a “normal” person, to bravado in an effort to confront the stigma (Goffman, 1986; Weiss et al., 2006). To avoid discrimination and exclusion, a person with a stigmatized illness may elect to avoid seeking care, leading to delays in treatment (Weiss et al., 2006).

Much of the stigma surrounding HCV may stem from stereotypes surrounding injection drug use (Dowsett et al., 2017). Such stereotypes may include the perception of injection drug users as being potentially violent or manipulative, or having poor motivation (van Boekel,
Brouwers, van Weeghel, & Garretsen, 2013). In the healthcare setting, stigma has taken the form of perceived blaming, disrespect, or judgmental behavior directed by clinicians (North, Devereaux, Pollio, Hong & Jain, 2012; Rogal et al., 2016; Skeer, Ladin, Wilkins, Landy, & Stopka, 2018).

Stigma in HCV may also manifest from misconceptions relating to transmission, such as the unfounded fear that HCV can be transmitted through everyday contact like sharing a dinner plate (Dowsett et al., 2017; North et al., 2014). In healthcare settings, it has taken the form of inappropriate infection control practices, such as unwarranted double-gloving and isolation (Moore, Hawley, & Bradley, 2009). Persons with HCV may be hesitant to disclose infection status for fear of stigma or discrimination (Moore et al., 2009; North et al., 2014). A veteran may be cautious about whom he or she discloses HCV status, adopting what has been referred to as a “need to know” approach, or preferring to confide only in trusted peers (Philips & Barnes, 2016b). Accordingly, the experience of stigma is increasingly understood to be a barrier to care among people with HCV (Miller, McNally, Wallace, & Schlichthorst, 2012; Rogal et al., 2016; Skeer et al., 2018).

**Trauma**

Exposure to traumatic events, such as combat experienced in the armed forces, can lead to neurological changes and associated decline in mental health (Steenkamp et al., 2012; van der Kolk, 2014). Psychological manifestations may include: hyperarousal, changes in affect and mood, feelings of guilt or worthlessness, intrusive thoughts, nightmares or flashbacks (van der Kolk, 2014; VA, 2018). As a syndrome, these symptoms can meet the threshold of PTSD (VA, 2018). As many as one-fourth of veterans with HCV have a diagnosis of PTSD (VA, 2014). However, given that many veterans experience symptoms of trauma without meeting the
threshold of a full PTSD diagnosis (Steenkamp et al., 2012), the prevalence of trauma-related symptomatology in this group is likely to be even higher.

Trauma can change the way the brain responds to stressful stimuli. For persons with trauma, even relatively benign occurrences could result in anger (van der Kolk, 2014). A traumatized individual may perceive his or her environment as hostile or come to anticipate negative outcomes (van der Kolk, 2014). A person with trauma may also become numb to stimuli, be they positive or negative (van der Kolk, 2014). Accordingly, it is possible that a person with trauma may underappreciate or outright ignore injury or illness. Ultimately, the original trauma may become superimposed on the attitudes, actions and perceptions that occur in daily life (van der Kolk, 2014). Perceptions of physical stimuli, emotional responses and interactions with others become filtered through the lens of trauma. In a self-protective effort, persons with trauma may undertake intense efforts to avoid reminders that trigger intrusive thoughts, agitation or negative emotions (van der Kolk, 2014; VA, 2018).

Previous findings suggest that increased severity of trauma symptoms may be associated with medication non-adherence among veterans with heart disease (Kronish, Edmondson, Li, & Cohen, 2012). Dissociation and other symptoms of trauma have also been associated with medication non-adherence among persons with Human Immunodeficiency Virus (HIV; Keuroghlian et al., 2011). Of importance, veterans with a diagnosis of both HCV and PTSD are also more likely to use alcohol and drugs to cope with PTSD symptoms than peers who experience symptoms of trauma but do not have the diagnosis of HCV (Oser, Cucciare, McKellar, & Weingardt, 2011). And while the actual diagnosis of PTSD does not preclude receipt of DAA’s among veterans (Lin et al. 2017), there is little evidence examining how individual posttraumatic symptomatology affects the choice to undergo treatment for HCV.
The Common-Sense Model

The Common-Sense Model (CSM; Leventhal et al., 2016) may be useful in examining how perceptions of illness, and experiences with stigma and/or trauma play a role in undergoing treatment among veterans with HCV. The strength of the CSM as a framework is its emphasis on the process of a person detecting and interpreting health threats and then formulating responses to manage them (Leventhal et al., 2016). Health threats, such as illness, are often first made evident by perceived symptoms (Leventhal et al., 2016). The identification of a health threat activates what is described within the CSM framework as a prototype. A prototype is a collection of memories based upon one’s history of sensations and physical and cognitive functioning during illness (Leventhal et al., 2016). For example: a person will build a prototype of streptococcal pharyngitis based upon how he or she felt while experiencing it, such as soreness and difficulty swallowing.

A prototype in turn activates illness representations, meaning the words or ideas that define a person’s perspective about a given illness and treatment (Leventhal et al., 2016). Illness representations are formed by the influences of culture, information gleaned from the media, and through interactions with people, including friends, family, and clinicians (Baumann, 2003; Leventhal et al., 2016). Important demographic factors, such as, race, ethnicity and gender influence illness representations (Baumann, 2003; Martin & Suls, 2003). Illness representations consist of: identity, meaning the signs and symptoms that define an illness; cause, meaning the factors that led to an illness; timeline, meaning the chronological course of an illness; consequences, meaning the perceived or expected outcomes of an illness, and finally; controllability, meaning the capacity to mitigate sickness or maintain health in face of an illness (Leventhal, Leventhal, & Breland, 2011; Leventhal et al., 2016).
Representations of a given illness, when matched to an appropriate illness prototype, inform an action plan of how to respond to that illness (Leventhal et al., 2016). This action plan defines the specific action to be taken (e.g. take medication), timing and placement of the action (e.g. every night before bed) and expected outcomes of the action (e.g. resolution of symptoms). As an action plan is initiated, illness representations evolve in response to new information and stimuli (Leventhal et al., 2011). Thus, action plans may adjust accordingly to address a health threat. Alternatively, if the action plan effectively addresses the health threat, then the existing prototypes and illness representations may be reinforced and called upon again, should the same health threat reoccur.

For an acute illness, such as the aforementioned streptococcal pharyngitis, the progression from health threat detection to action plan may be simple. A sore throat activates the prototype of a streptococcal pharyngitis. This is matched to representations of this illness, as characterized by: identity, cause, timeline, consequences, and controllability. This in turn informs an action plan that may include visiting a clinician. Should symptoms resolve, the prototype and illness representations are reinforced if the individual experiences streptococcal pharyngitis again at a later date.

However, for a chronic or asymptomatic illness, such as HCV, the pathway from threat detection to action plan may be more ambiguous (Leventhal et al., 2016). The typical silent nature of HCV (CDC, 2019) may result in an illness prototype that is similar to normal functioning, such that the illness effectively becomes a part of everyday life (Leventhal et al., 2016). The activation of the prototype in HCV might then rely on individual experiences and feelings that are associated with the prototype. Awareness of HCV infection, and subsequent new knowledge following diagnosis, may be paired with experiences, feelings or mental states.
related to events that preceded and led to HCV testing.

**Prototypes and Representations of HCV Among Veterans**

Previous findings among veterans who have been treated for HCV suggest they acknowledged the progressive and potentially fatal course of this infection and its sequelae (Clark & Gifford, 2015; Phillips & Barnes, 2016a). These veterans likely possessed a representation of HCV that is reflective of a long-lasting and severe illness (representations of timeline and consequences respectively). This is similar to findings from qualitative research utilizing the CSM in a non-veteran population, which suggested that patients undertook treatment after witnessing others with HCV dying from the sequelae of the infection (Safo, Batchelder, Peyser, & Litwin, 2015). Moreover, findings suggest that veterans may consider HCV infection to be controllable through a combination of treatment, personal resolve, and discipline (Clark & Gifford, 2015; Phillips & Barnes, 2016a). As veterans treated with the new medication confide in their peers (Phillips & Barnes, 2016b), the old “horror stories” of INF-RBV (Groessl et al., 2008) may become a thing of the past. As the VA provides greater access to the new medications (Graham, 2016), and more veterans seek and receive treatment (Moon et al., 2017), the prevailing representation may become that HCV is a controllable illness, perhaps making treatment more feasible.

**Stigma and trauma in the HCV prototype.** While a veteran may perceive treatment of HCV to be feasible and necessary (i.e. controllability and consequences), the exposure to stigma and/or trauma may influence his or her prototype and interfere with action planning (Figure 1). Experiences of trauma may become integrated into a prototype by way of the dominant cause of HCV: injection drug use (CDC, 2018). Veterans with PTSD are at increased risk of developing substance use disorders (Wisco et al., 2014), which may result from engaging in substance use to
moderate symptoms of trauma (Jacobsen, Southwick, & Kosten, 2001). If such activity resulted in HCV infection, then trauma may become integral to the prototype. In understanding the numbing effects of traumatic response (van der Kolk, 2014), a diagnosis of HCV may go unheeded. A veteran may steer clear of care and treatment to avoid reminders of the trauma, particularly if the diagnosis itself was traumatizing (Morais-de-Jesus, 2014). He or she may distrust others who haven’t shared their experiences (van der Kolk, 2014). Such distrust may be extended to clinicians. Such avoidance may be reinforced by experiences of stigma that may result from having a mental health diagnosis (Mittal et al., 2013).

Similarly, stigma in the HCV prototype may conjure shame in a veteran whose illness was transmitted through injection drug use (Phillips & Barnes, 2016b). As a result, he or she may feel that they are less deserving of treatment (Skeer et al., 2018), and thus avoid seeking care. And even if the veteran’s illness representation is such that HCV is controllable, he or she may not be willing to seek treatment if he or she is uncertain he or she will receive appropriate and compassionate care (Rogal et al., 2016). Alternatively, a veteran may feel the need to prove himself or herself as one who is reliable when faced with skepticism among clinicians (Clark & Gifford, 2015).

In these examples, there is a mismatch between the HCV prototype, and the representation that HCV treatment is warranted (HCV being both consequential and controllable). As representations are filtered through memories of stigma and/or trauma, the prototype effectively alters the representation of HCV, to reflect an illness that is no longer controllable. In turn, the action plan defaults to avoiding treatment. With no new feedback to stimulate re-appraisal of the prototype and representations, this action plan could continue,
perhaps even until advanced symptoms of HCV manifest. Further, subsequent experiences of stigma and/or trauma may only reinforce treatment avoidance.

**Research and Clinical Implications**

The CSM provides a framework for future studies seeking to understand how veterans choose to initiate treatment for HCV. The CSM may also be used to guide investigation of treatment initiation in other populations similarly affected by stigma and/or trauma. This may include those with HIV infection (Brezing, Ferrara, & Freudenreich, 2015; Chambers et al., 2015).

In the clinical setting, open-ended questions such as “What do you think caused your HCV?” or “How have you felt different after learning you have HCV?” may be helpful in unearthing representations of illness. Similar discussions may also reveal underlying stigma and/or trauma related to the diagnosis. In exploring and addressing these experiences, a clinician may be able to encourage a veteran to seek treatment, where otherwise he or she may be reluctant to do so. This is particularly important given the high comorbidity of mental health and substance use diagnoses among veterans with HCV (VA, 2014).

**Conclusion**

Veterans are disproportionately affected by HCV (Backus et al., 2014; Denniston et al., 2014). With the introduction of effective treatment for HCV (Afdhal et al., 2014), and the risk of increased HCV infections in the wake of the injection opioid epidemic (Jones et al., 2017; Zibbel et al., 2018), there is an impetus to gain a more thorough understanding of how veterans make the choice to undergo treatment. Notwithstanding multiple influences upon the decision to seek treatment, exposure to and experience with stigma and/or trauma is pervasive among veterans (Dowsett et al., 2018; VA, 2014). It is proposed here that experiences of stigma and/or
trauma associated with HCV infection can result in a prototype that is primed for treatment avoidance. Exploration into the illness representations of veterans who have been treated for HCV infection may provide insight into how they navigated stigma and/or trauma to undertake an action plan to promote treatment.
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AN EXPLORATION OF THE INFLUENCE OF STIGMA AND TRAUMA


Appendix

Figure 1: Application of Common-Sense Model to HCV Treatment Decision Making.

*Note.* HCV = Hepatitis C Virus. Arrows indicate progression.
Chapter 3: Manuscript 2
Is There a Place for Theoretical Frameworks in the Qualitative Paradigm?

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Abstract

The qualitative paradigm proceeds from the position that there is no one observable reality. Researchers utilizing qualitative methods build findings inductively, from raw data to a conceptual understanding. Theoretical frameworks may be utilized to guide qualitative analyses by suggesting concepts and relationships to explore. The framework may provide a sense of the story emerging from the analyses. And concurrently, the rich description provided by the analyses may allow it to be more deeply appreciated. However, there is a risk that using a theoretical framework may stifle inductive reasoning or result in findings incongruent to the data. The following is a discussion of the application of a theoretical framework in a qualitative study. This study, guided by the Common-Sense Model, explores the choice to undergo treatment for hepatitis C virus among veterans. Examples from the analyses are provided to facilitate discussion on the utilization of a theoretical framework. Techniques to optimize the use of a theoretical framework, as well as mitigate risks of such use, are presented. When utilized alongside rigorous data analyses and introspection, a theoretical framework may serve as a valuable tool to navigate data.

Keywords: Grounded theory, methods in qualitative inquiry, Strausarian GT, philosophy of science, constructivist GT, theoretical frameworks
The qualitative paradigm proceeds from the premise that reality is constructed by those who live it, since perceptions about phenomena are conditioned by experience (Corbin & Strauss, 2012; Miles, Huberman, & Saldaña, 2020; Lincoln & Guba, 1985). Therefore, there can be no one observable reality (Lincoln & Guba, 1985). The methodology of the qualitative paradigm is to build inductively from the ground where the data are, to a more distilled, conceptual understanding (Lincoln & Guba, 1985).

A theoretical framework may provide utility in qualitative analyses. Theoretical frameworks describe concepts and relationships in a given phenomenon, effectively providing a map for qualitative exploration (Miles et al., 2020). Such frameworks may have been built inductively from previous research or based upon existing theories or literature (Miles et al., 2020). On the one hand, a framework may provide a sense of the story as it emerges out of the analyses, leading down paths of inquiry that may otherwise be missed (Sandelowski, 1993). In this manner, a question regarding the phenomenon becomes a gateway to the investigation, the theoretical framework suggests an orientation, and rigorous data analysis yields findings (Corbin & Strauss, 2012; Miles, et al, 2020; Sandelowski, 1993). On the other hand, the theoretical framework can be more deeply appreciated because of the rich description provided by the analysis (Corbin & Strauss, 2012; Sandelowski, 1993). The framework is elaborated further by its fit to the data, and the data are comprehended in a new light. However, there are concerns that the use of a theoretical framework may bias findings or stifle inductive discovery (Corbin & Strauss 2012; Morse, 1992). With these concerns in mind, the goal becomes one of maximizing the utility of a theoretical framework, without distorting the data into an anticipated framework (Corbin & Strauss 2012).
The Common-Sense Model as Applied to Hepatitis C Virus Among Veterans

The following is an example of the process of using a theoretical framework in the qualitative paradigm. The authors are conducting a study to explore how veterans with hepatitis C virus infection (HCV) navigate challenges and choose to undergo treatment. Open and axial coding, a method of analysis in grounded theory, served as the analytic tool to understand emerging concepts and relationships (Corbin & Strauss, 2012). Participants provided written informed consent to participate in this study. This study was approved by the institutional review boards at the Edith Nourse Rogers Memorial Veterans Hospital, where the study was conducted (Project ID: 1192875; Project Number 0014), as well Northeastern University, the first author’s academic institution (IRB Number 16-09-07).

Hepatitis C virus infection (HCV) is chronic and largely asymptomatic but presents significant risks for hepatocellular carcinoma and cirrhosis over time (Centers for Disease Control and Prevention [CDC], 2020). Previously, treatment options were limited to less-effective injection-based regimens, such as a combination of Interferon and Ribavirin (INF-RBV; (McHutchinson, et al., 2009). These treatments were associated with flu-like and psychiatric side-effects in some patients (McHutchinson, et al., 2009). However, recent advances in effective and tolerable direct-acting antiviral medications (DAAs) have presented realistic options for a cure for this chronic illness (Afdahl et al., 2014; Moon, Berry, & Ioannou, 2017).

Knowing the risks involved with HCV, and the availability of effective treatment, one would not be faulted for assuming that the choice to undergo treatment would be a logical one. However, choices are not always based upon careful consideration of risks and benefits, but instead may rely upon subjective experience (Jones & Oliver, 2007; Slovic, 1999). For veterans,
who are disproportionately affected by HCV (Hofmeister et al., 2019; Noska, Belperio, Loomis, O’Toole, & Backus, 2017), such experiences may include stigma and/or trauma.

Stigma in HCV largely occurs due to the association with injection drug use (Dowsett, Coward, Lorenzetti, MacKean, & Clement, 2017), the predominant transmission route (CDC, 2020). Stigma, in the form of perceived disrespect or stereotyping in the healthcare setting, may discourage veterans from seeking care (Rogal et al., 2016). Further, symptoms of trauma are common among veterans with HCV (United States Department of Veterans Affairs [VA], 2014). The symptoms of dissociation, numbness, guilt or agitation borne from trauma (American Psychiatric Association [APA], 2013; van der Kolk, 2014), may result in a veteran minimizing the threat posed by HCV. In the face of such challenges, the treatment for HCV, an illness with potentially distant consequences, becomes a distant priority. How then does a veteran living with such challenges choose to undergo treatment for such an illness?

The Common-Sense Model (CSM; Leventhal, Phillips, & Burns, 2016) was selected as a theoretical framework to guide analyses in this study. In this framework, memories of sensations and experiences connected to illness and health form a construct known as a prototype. These prototypes activate what is described in the CSM as illness representations, which serve as mental schematics for a given illness at a given point in time (Leventhal et al., 2016). Representations of illness are constructed by individuals and are informed by these prototypes, as well as the influences of race, gender, culture, media, and interactions with others (Baumann, 2003; Leventhal et al., 2016; Martin & Suls, 2003). Together, prototypes and illness representations form one’s perception of a given illness, comprising five domains: 1) identity, or symptomatology, 2) cause, 3) controllability, 4) timeline and 5) consequences (Leventhal et al., 2016). The memories and sensations incorporated into prototypes are matched to illness
representations along these domains to inform a construct known as an action plan (Leventhal et al., 2016). This consists of a specific action to be taken, such as taking medication, the timing of that action, and the expected outcome, such as resolution of symptoms. In this way, action plans direct the means by which to address a health threat.

For example, a person may possess a prototype of an acute illness such as viral pharyngitis based on symptoms that include a sore throat. When this person later experiences a sore throat, the prototype activates a representation of identity that effectively states, “this pain means I have pharyngitis”. The prototype then activates and matches to a representation of controllability, which suggests that cool liquids may be used to ameliorate symptoms. Thus, an action plan is formed to rest and drink cool beverages as needed for symptom relief. The illness prototypes and representations then adjust to new information (Leventhal, Leventhal, & Breland, 2011), depending on the outcome of the action plan. If this action plan results in a resolution of symptoms, then the prototype and representations may be reinforced, to be called upon again should the illness reoccur (Cameron & Leventhal, 2003). If symptoms do not improve, then there may be a mismatch between the representation of controllability and the underlying illness as originally defined by the prototype (Leventhal et al., 2016). Perhaps this person will later learn he or she actually has streptococcal pharyngitis, which may require additional clinical intervention. Should symptoms then resolve following intervention, the prototype and representations are revised (Leventhal et al., 2011), to account for the potential of either viral or streptococcal pharyngitis.

Findings from literature suggest that some veterans perceive HCV as potentially life-threatening (Clark & Gifford, 2015; Phillips & Barnes, 2016). Such views may encompass a representation of consequences, which suggest that treatment of HCV is warranted. However,
recall that representations are activated by prototypes, which are themselves often first activated by symptoms (Leventhal et al., 2016). Given that HCV is a largely asymptomatic illness (CDC, 2020), the prototype of HCV may instead default to those emotions and memories that are aroused when one is reminded of his or her infection (Garvey & Jones, 2019). In the case of injection drug use, these may involve experiences of stigma (van Boekel, Brouwers, Weeghel, & Garretsen, 2013) and/or trauma (Wisco et al., 2014). Such a prototype may indicate that HCV treatment is to be avoided. This may occur if a given individual experiences stigma, and comes to feel undeserving of treatment (Skeer, Ladin, Wilkins, Landy, & Stopka, 2018), or because symptoms of trauma have desensitized this individual to a health threat (van der Kolk, 2014). Such prototypes are effectively in-conflict with representations that suggest that HCV can have significant health consequences (Garvey & Jones, 2019). If such is the case, then it is possible that a veteran possessing a prototype of stigma and/or trauma might not seek treatment, even if he or she understands the consequences of such a course of action.

The Common-Sense Model Applied to Veterans with HCV

Consistent with the literature, most veterans in this study perceived HCV to be an asymptomatic, chronic illness, with the potential to cause severe liver damage in the years following diagnosis. “…it’s a silent killer.” one veteran explained. Another veteran offered a metaphor: “…if every day someone’s putting a grain of sand in your pocket, you don’t notice it. Now your pockets weigh ten pounds apiece…” These and similar statements, were categorized under a theme named “Adding Sand to Your Pocket” to represent the view that HCV was a slow, insidious disease. This theme encompassed three illness representations: identity, timeline, and consequences.
Matching Prototypes to Representations to Inform an Action Plan

These above representations may encourage seeking treatment. However, for such an action plan to be formulated, they must be matched to a prototype that suggests the consequences of HCV are worth avoiding. One such match occurred when a veteran sought to move on from a past that involved trauma and cocaine use. As one veteran stated: “…there is a darn good reason why the windshield is so much bigger than the rear-view mirror. Because what’s important is in front of you, not behind you.” This and similar statements were categorized under a theme named “In the Rear-View Mirror”, to represent the desire to move forward with life, toward a healthy future. This prototype matched to representations of consequences, suggesting that the sequelae of HCV should be avoided for the sake of one’s future. Thus, an action plan was formulated to treat HCV. “Better deal with it now…” as another veteran stated.

Mismatches between Prototypes and Representations

However, for one veteran, the understanding of the consequences of HCV did not motivate seeking treatment. “…at the age I was at, I figured I’d just outlive it. You know, I’d probably not be here, when my liver became cirrhotic.” He elaborated further: “…tell you the truth, I was already living on borrowed time…” This position was supported by the asymptomatic nature of HCV. “…I didn’t know what I was supposed to feel…after having this condition all of these years, I never felt any different.” Further discussion with the veteran revealed trauma stemming from early life in a gang environment, coupled with the stressors of serving as a combatant in Vietnam. “I had been a fighter since I was eight years old…one extreme to the next…you go from using your fists to using knives, eventually using pistols.” He elaborated further: “I was concerned about not getting shot and not getting stabbed in my growing-up experience.” These experiences were reflected in how he approached HCV in later
life. “…when you’ve lived the kind of life I’ve lived, if there wasn’t something immediately affecting your health, your mental health…you didn’t give it much thought. I didn’t anyway.” Such a subdued response to injury or illness may occur in persons with histories of trauma (van der Kolk, 2014; APA 2013). With these experiences in mind, this veteran was largely uninterested in treatment for his HCV. “Had I have been younger it might have been a different situation. But at my age, it didn’t really make a difference. Especially because it didn’t hurt.”

This veteran recognized that HCV could result in cirrhosis, reflecting a representation of consequences. However, potentially traumatic experiences in his past appeared to have been incorporated into this veteran’s illness prototype. The illness in question, infection with HCV, presented with no symptoms, and thus the prototype was limited to experiences of trauma that suggested that those issues which do not pose an immediate threat were to be minimized. The consequences suggested within the prototype and the illness representation were in conflict. This veteran’s prototype, as it existed at the time, did not match to the representation of consequences, and so and the action plan defaulted to the experiences contained in the prototype. Thus, the consequences of illness, cirrhosis and liver cancer, were rendered unimportant, and the action plan to seek treatment was not entertained.

This veteran was fully prepared to live out the rest of his life without treatment, despite knowing the potential consequences. However, prototypes and representations are dynamic, and change in response to new stimuli (Leventhal et al., 2011). In this case, the veteran was eventually convinced to undergo treatment by two clinicians who took interest in his care. “If these (clinicians) were so convinced that it would be a benefit for me, it was almost like I was…doing it because they wanted me so much to do it.” As he explained further: “Had it have been a weaker person…that really didn’t show that kind of intense interest, I probably wouldn’t
have done it.” The veteran looked back fondly on the interaction with his clinicians, saying “…I don’t think these (clinicians) are here now, because if they were, I would kind of make it my business to try to see them, to thank them.”

This veteran’s original prototype that incorporated trauma was superseded by a new prototype that had incorporated the compassion of the clinicians, who felt that treating his HCV was good for his health. This new prototype activated, and was matched to, his representation of consequences, suggesting that sequelae like cirrhosis is something to be avoided. Thus, a new action plan was formed to take oral treatment for his HCV. And despite earlier reluctance, he was glad to have been treated. “…(HCV) was never at the forefront of my mind, but it was there. So at least if (treatment) worked I could get rid of that. That’s just…one thing I wouldn’t have to carry.”

**Utilizing Theoretical Frameworks**

Elaborating on the analogy of theoretical frameworks as maps (Miles et al., 2020), consider data in a qualitative study to be represented by an island. We know that on this island there is a treasure (findings). It is certainly possible to roam the island (without a framework) looking for signs of the treasure, but for every lead there may be a dozen dead ends. Thus, it may be helpful to bring along a treasure map, or in this case, a theoretical framework, to aid in navigation (Miles et al., 2020). We know that it was made by someone who knows where the treasure is hidden based on their own experience (evidence from literature; Miles et al., 2020). It provides landmarks (theoretical orientation, concepts and constructs) and suggested paths (processes and relationships) through the island (Corbin & Strauss, 2012; Sandelowski, 1993). However, in trying too hard to stick to the map (warping data to fit the framework, or rote positioning of the data into a priori categories) one might lose sight of the actual goal (answering
the research question; Corbin & Strauss, 2012; Morse, 1992; Sandelowski, 1993), or return home with an empty chest (producing findings that are incongruent to the phenomenon). In using the map, one must still use one’s skills and instincts to navigate the island (methodical coding, reflection, and writing; Corbin & Strauss, 2012; Morse, 1992). Keeping that in mind, however, a treasure map may prove to be a valuable tool.

The risks in utilizing a framework may be mitigated by exploring the fit between the data and the framework, and thoughtfully questioning when and how it will be used (MacFarlane & O’Reilly-de-Brún, 2012; Sandelowski, 1993). The researcher, at each stage of inquiry, asks whether the research would be benefited or detracted by use of the theoretical framework (Sandelowski, 1993). In this way, the researcher maintains a stance of uncertainty, and remains open to the possibility that the data may not fit the chosen framework, and if so, its use should be abandoned (Corbin & Strauss, 2012). If it turns out that the map isn’t leading to the treasure, then it becomes a discussion among shipmates (research team members). Together, they might decide to use a different map (a new framework) or decide to rely on one’s own skills to find the treasure (analyze without a framework to discover emergent themes; Lincoln & Guba, 1985).

Further means of mitigating bias include maintaining memos, a process of keeping records of thoughts, feelings and discoveries related to research (Corbin & Strauss, 2012; Guba & Lincoln, 1981). In this way, memos provide an audit trail and provide evidence for coding decisions, and a means of tracing back steps should one encounter a dead end. Collaboration with other researchers well-versed in the phenomenon or population (Patton, 1999) can also provide a fresh set of eyes to a researcher who may be leaning too far in one direction or another. In this way, the risk of presenting findings that are incongruent to the context of the phenomenon can be reduced.
Lastly, it is important to consider the type of qualitative study one is conducting, and the appropriateness of a theoretical framework in data analysis. The method of open and axial coding utilized in this study was chosen based upon the emphasis placed in grounded theory upon the interaction of multiple factors in social processes (Corbin & Strauss, 2012). However, early scholars of grounded theory emphasized that findings should be derived primarily from the data, without presuppositions (Glaser & Strauss, 1999/2017), which may include theoretical frameworks. Therefore, the utilization of a theoretical framework is potentially controversial when utilizing this methodological approach. Later scholars of grounded theory posited that theoretical frameworks may orient and guide analyses, so long as findings are derived from original data and investigators maintain a reflexive stance (Corbin & Strauss, 2012). Thus, it was determined by the authors that the use of the CSM in this study was appropriate. Another qualitative researcher using open and axial coding may have thought differently, preferring to rely solely on rigorous induction to avoid the risk of warping the data (Morse, 1992), and develop new a theory from the ground-up (Glaser & Strauss, 1999/2017). Ultimately, the utilization of a theoretical framework is left up to the best judgement of the researcher.

Conclusion

Qualitative research is a process of discovery, with new knowledge being a product of both the researcher’s interpretation of the story depicted by the data (Lincoln & Guba, 1985). Depending on one’s qualitative approach, a theoretical framework may be useful to guide analysis and suggest avenues of exploration (Corbin & Strauss, 2012; Miles, et al., 2020; Sandelowski, 1993). The application of a framework in qualitative research depends upon methodical analysis, as well as thoughtful reflection of the applicability of the framework (MacFarlane & O’Reilly-de-Brún, 2012; Sandelowski, 1993). Over-reliance on a framework
runs the risk of telling a story that is not true to the phenomenon under study (Morse, 1992). However, should one retain a navigator’s sight, and thoughtfully question the meaning behind data, a theoretical framework can serve as a valuable map on the way to meaningful discovery.

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**Declaration of Conflicting Interests**

The authors declare that there is no conflict of interest.
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Chapter 4: Manuscript 3
An Exploration of the Influence of Stigma and Trauma in the Illness Representations of those Veterans who Decided to Initiate Treatment for Hepatitis C Virus

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Abstract

Hepatitis C Virus infection (HCV) is a blood-borne infectious disease that presents a long-term risk for cirrhosis and hepatocellular carcinoma, despite being otherwise largely asymptomatic. Veterans in the United States (U.S.) are disproportionately affected by HCV and contend with challenges that may complicate treatment initiation. These challenges include stigma, which has been recognized as a barrier to care, as well as symptomatic responses to trauma, which may discourage treatment seeking. The following qualitative study sought to understand, in the face of these challenges, how veterans decided to initiate treatment with current oral direct-acting antiviral medications (DAAs). The Common-Sense Model (CSM) provided a theoretical framework to understand how illness perceptions or illness representations influenced the decision to initiate treatment. Use of this framework further helped to elucidate how illness representations may be influenced by experiences of stigma and/or trauma via prototypes or mental structures surrounding illness. Analyses by open and axial coding suggested that the veterans in this study recognized the risks of liver disease and possible death posed by HCV, forming a representation of consequences. They also understood that there were effective medications to treat HCV, forming a representation of controllability. However, memories and emotions surrounding stigma, trauma and substance use may have constituted prototypes that were mismatched to representations of HCV controllability and consequences, and thereby, discouraged treatment initiation. Veterans with such experiences overcame stigma, or reframed trauma and substance use in the light of ongoing recovery, forming new prototypes of HCV. These new prototypes matched the representations of controllability and consequences, which had conferred the need for treatment. The findings of this study have implications for further
research into the care of veterans with HCV who contend with stigma, trauma, and substance use.
Introduction

Hepatitis C Virus (HCV) is a blood-borne pathogen that can be asymptomatic for years but is associated with cirrhosis and hepatocellular carcinoma in the long-term (Centers for Disease Control and Prevention [CDC], 2020). Infection with HCV is predominantly transmitted through sharing of contaminated needles (CDC, 2020). Of the approximately 5.7 million veterans who received outpatient care through the Veteran’s Affairs (VA) health system in 2015, HCV prevalence was 3.1% (approximately 177,000 individuals; Noska et al., 2017). This is compared to the approximate 1% prevalence in the total United States (U.S.) population between 2013 and 2016 (Hofmeister et al., 2019).

Until recently, the primary treatment for HCV were injections of Interferon, often in combination with oral Ribavirin (McHutchinson et al., 2009). Treatment could take up to a year, and the regimen presented the potential for flu-like and psychiatric side-effects (McHutchinson et al., 2009). Further, treatment with Interferon was associated with a low rate of achieving a sustained virologic response (SVR) or undetectable viral load. The effectiveness of this treatment was reported to be as low as 38% in some cases (McHutchinson et al., 2009). Recent developments in oral direct-acting antiviral medications (DAAs) have brought realistic options for a cure (Moon, Green, Berry, & Ioannou, 2017). These DAAs include the oral combination of Glecaprevir and Pibrentasvir, which features an SVR rate ranging from 83% to 100%, and present with tolerable side-effects for most patients (Kwo et al., 2017).

The advent of DAAs comes at an opportune time. With the ongoing opioid epidemic (Jones, Christensen, & Gladden, 2017), the incidence of HCV has increased accordingly (Zibbel et al., 2018). This presents an impetus to gain a greater understanding of how affected populations, such as veterans, choose to initiate treatment.
Because of its association with injection drug use there is considerable stigma attached to HCV infection (Dowsett, Coward, Lorenzetti, McKean, & Clement, 2017). Stigma is understood to be a potential barrier to HCV care and treatment (Miller, McNally, Wallace, & Schlichthorst, 2012; Rogal et al., 2016). In addition to stigma, U.S. veterans with HCV contend with a host of other challenges, including trauma (VA, 2014). Symptoms of a traumatic response, including numbness, agitation and resultant avoidance, may also present challenges to seeking care (van der Kolk, 2014). Given that HCV is a frequently asymptomatic illness that often presents with distant consequences, it is possible that treatment may not be seen to be a priority for veterans contending with these challenges.

The present qualitative study sought to address the question of how veterans, who may have experienced stigma and/or trauma, navigate these challenges to initiate treatment for HCV. The Common-Sense Model (CSM; Leventhal, Phillips, & Burns, 2016) was utilized in this study to frame the understanding of the role of stigma and/or trauma in treatment among veterans with HCV. Nine veterans were recruited for face-to-face, in-depth interviews to discuss their experiences of HCV diagnosis, perceptions of their illness, exposure to stigma or trauma, and how they decided to get treated.

**HCV Among U.S. Veterans**

More than 90% of veterans receiving care within the VA are men (VA 2020c), so it is understandable that most of those with HCV at the VA are men (96.5% men vs 3.5% women; Noska et al., 2017). Veterans born between the years 1945 and 1965 have the highest prevalence (10.3% among men, and 4.7% among women: compared to 1.2% and 0.7% prevalence among men and women respectively born after 1965; Backus, Belperio, Loomis, & Mole, 2014). Black or African American veterans have the highest prevalence (11.8%), compared to Latinx veterans.
(6.4%) and white veterans (4.8%; Backus et al., 2014). Veterans who are homeless have a prevalence of HCV more than four times that of veterans who are not homeless (12.1% vs. 2.7%; Noska et al., 2017).

Annual rates of HCV treatment initiation in the VA have increased dramatically following the introduction of DAAs. An 8.5-fold increase in treatment was observed between 2010 and 2015 (Moon, et al., 2017). Access to treatment with DAAs had previously been complicated by costly medication coupled with high demand (Graham, 2016). Further complications included limited treatment locations and fragmented care between VA and non-VA sites (Tsai et al., 2017). The VA has sought to address these issues by expanding eligibility for DAA prescription to all patients with HCV in-system, regardless of whether the infection was service-connected (Graham, 2016). The VA has also eliminated requirements for a liver biopsy prior to treatment, as well as requiring a minimum period of abstinence from substance use prior to treatment (VA, 2020a). Veterans may also be eligible for free or reduced cost of medication copays, depending on a veteran’s disability and income (VA, 2020b).

Within the VA, African American or Black veterans, along with Latinx veterans, are less likely to receive treatment than their white counterparts (Lin et al., 2017). Further, despite elimination of institutional substance-use abstinence requirements, veterans with substance use diagnoses are less likely to be treated with DAAs (Lin et al., 2017). It is estimated that as many as 15,000 veterans remain untreated for HCV in the VA system (VA, 2020a).

**Stigma and Trauma in HCV**

Stigma experienced over the course of HCV infection may complicate the decision to initiate treatment. Stigma is defined as a personal feature that results in experienced or perceived denigration and exclusion by others, or personal feelings of shame or self-derision (Goffman,
1986; Weiss, Ramakrishna, & Somma, 2006). Such reactions result from stereotypes attached to those features (Goffman, 1986), such as, the perception by others that injection drug users are poorly motivated or manipulative (van Boekel, Brouwers, Weeghel, & Garretsen, 2013). The experience of stigma in HCV may also vary depending on whether an individual is also infected with Human Immunodeficiency Virus (HIV; Saine et al., in press), which is also a stigmatized illness (Chambers et al., 2015).

Stigma may also occur in the healthcare setting where it can take the form of perceived disrespect, dismissal, or judgement (Rogal et al., 2016; Skeer, Ladin, Wilkins, Landy, & Stopka, 2018). Even standard precautions by clinicians, such as labeling specimens as hazardous, while not intended as stigmatizing (Weiss, 2006), may be viewed as such by persons with HCV (Rogal et al., 2016). This may be exacerbated by an inadequate understanding of transmission risks among persons with HCV, which has been suggested in previous research (North, Devereaux, Pollio, Hong, & Jain, 2013). For these reasons, stigma is understood to be a potential barrier to effective care and treatment among persons with HCV (Miller, et al., 2012; Rogal et al., 2016).

Yet, there is limited evidence discussing the role of stigma as it relates to an individual’s perceptions of illness, and in how veterans decide to initiate treatment.

Further, many veterans with HCV contend with exposure to trauma and its sequelae (VA, 2014). Traumatic events may include, but are not limited to, combat exposure, accidents and sexual assault (American Psychiatric Association [APA], 2013; van der Kolk, 2014). Exposure to such events has the potential for long-lasting effects on mental health (APA, 2013; van der Kolk, 2014). The sequelae from trauma may take the form of numbing, hypersensitization to even benign stimuli, and intrusive symptoms, such as flashbacks or nightmares (APA, 2013; van der Kolk, 2014). Trauma may also result in negative mood or affect changes, such as depression.
or self-blame (APA, 2013). Persons experiencing trauma may accordingly take self-protective measures to avoid reminders of trauma that may trigger agitation or shame (APA 2013; van der Kolk, 2014). Combined, these symptoms may meet the threshold for diagnosis of post-traumatic stress disorder (PTSD; APA, 2013). As many as one-fourth of veterans with HCV also have a diagnosis of PTSD (VA, 2014). However, given that one may experience trauma-related symptoms without meeting the full criteria for diagnosis (Steenkamp et al., 2012), the prevalence of traumatic symptomatology in this population may well be higher.

Findings from previous research suggest that trauma-related symptomatology negatively affects health behaviors, in particular, medication adherence (Kronish, Edmondson, Li, & Cohen, 2012; Zen, Zhao, Whooley, & Cohen, 2012). One study of veterans with heart disease demonstrated that those with PTSD were nearly twice as likely to report skipping medication doses than those without PTSD (Kronish et al., 2012). Similarly, research among persons with Human Immunodeficiency Virus (HIV) demonstrated that trauma-related dissociation was associated with non-adherence to prescribed medication (Keuroghlian et al., 2011). One finding of a retrospective cohort study of veterans with HCV (N=84,221), indicated that a PTSD diagnosis did not decrease the likelihood of the veterans initiating treatment with DAAs (Lin et al., 2017). However, veterans with PTSD are also more likely to have a history of substance use (Wisco et al., 2014), which has been demonstrated to decrease the likelihood of their treatment initiation with DAAs (Lin et al., 2017). There is a need to explore the veteran’s perspective of how experiences of trauma and substance use affect their decision to initiate HCV treatment.

**The Role of Illness Representations and Prototypes**

The Common-Sense Model (CSM; Leventhal et al., 2016) was utilized in this study to frame an understanding of the roles of stigma and trauma in what could be a complicated path to
the decision to initiate treatment. The CSM has been similarly utilized in research of self-care management among persons with HIV (Reynolds et al. 2009), and HCV among a non-veteran sample (Safo, Batchelder, Peyser, & Litwin, 2015).

According to the CSM, illnesses are most often first recognized by the sensations or symptoms they produce (Leventhal, et al., 2016). These sensations activate a prototype, which is a construct consisting of personal memories and experiences of a given illness and its treatment. Importantly, prototypes also define one’s own perceived functioning and cognition when sick and when well. Prototypes in-turn activate perceptions known as illness representations, which serve as mental schematics to define a given illness and its treatment options in a set period of time. (Leventhal et al., 2016). These representations may be influenced by friends, family, clinicians, and the media (Baumann, 2003; Leventhal et al., 2016). Illness representations may also be influenced by culture, ethnicity, race, and gender identity (Baumann, 2003; Martin & Suls, 2003). Both the prototypes and representations of illness consist of 1) the identity of the illness, or symptoms, 2) the perceived cause of the illness, regardless of factual accuracy, 3) the physical, emotional and social consequences of the illness, 4) the anticipated timeline of the illness, and, 5) the controllability of the illness (Leventhal et al., 2016; Leventhal, Leventhal, & Breland, 2011).

The experiences incorporated into prototypes, when matched to illness representations, inform action plans to address health threats (Leventhal et al., 2016). These include specific actions to be taken, the timing of those actions, and their expected outcome. For an illness with clear symptomatology, such as asthma, the progression from prototype to illness representation and to action plan may be relatively clear (Leventhal et al., 2016). For example, a person with asthma builds a prototype of his or her illness based on symptoms of shortness of breath. The
next time this person experiences shortness of breath, the prototype activates a representation of identity that associates this symptom to asthma. This representation serves as a part of the schematic and conceptual understanding of asthma for this person. Based on knowledge gained from experience and visits to a clinician, this person knows that such symptoms can be mitigated through the use of an inhaler, a representation of controllability. Thus, this person constructs an action plan to: 1) use the inhaler, 2) at the onset of shortness of breath, 3) to resolve symptoms. Depending on the effectiveness of the action plan, prototypes and illness representations will then further evolve to better address the health threat in the future (See Figure 1; Cameron & Leventhal, 2003).

Findings from previous qualitative research among veterans treated for HCV suggest an understanding that HCV is a potentially fatal illness (Clark & Gifford, 2015, Phillips & Barnes, 2016a). This is similar to findings from non-veteran studies framed in the CSM (Safo et al., 2015). Moreover, findings suggest that some veterans believe that HCV is controllable through medication and personal actions (Clark & Gifford, 2015; Phillips & Barnes, 2016a), and that they are hopeful for a cure (Skolnik et al., 2019). These views reflect representations of consequences and controllability, suggesting that treatment is worthwhile.

However, these representations are matched to a prototype in order to produce an action plan to initiate treatment (Leventhal et al., 2016). Should experiences of stigma and/or trauma pervade the prototype, there may be a mismatch to a representation that suggests HCV is worth treating (see Figure 1; Garvey & Jones, 2019). For example: If a veteran was infected with HCV as a result of injection drug use utilized to cope with symptoms of trauma (Haller & Chassin, 2014), then that trauma may become integrated into his or her prototype of HCV (Garvey & Jones, 2019). The diagnosis of HCV alone may also be perceived to be traumatic (Morais-de-
Jesus, et al., 2014). In such scenarios, discussion of HCV could be triggering. As a result, a veteran may avoid discussion in order to avoid triggering symptoms of trauma (APA, 2013; van der Kolk, 2014). Here, there is a mismatch between representations of HCV that suggest the illness is controllable, and a prototype that becomes an obstacle to treatment. As a result, the veteran may default to the course of action suggested by the prototype.

Similarly, a veteran who had previously experienced stigma related to HCV may integrate those memories into his or her prototype (Garvey & Jones, 2019). The veteran may feel ashamed of the diagnosis, or actions that led to the diagnosis. This shame may cause one to feel undeserving of treatment (Skeer et al., 2018; Williams et al., 2019). If stigma is encountered in the clinical setting (Rogal et al., 2016), a veteran may be unwilling to seek care to avoid discrimination (Weiss, 2006). As before, there is a mismatch between the representation of controllability of HCV, and a prototype that discourages seeking treatment.

In the face of pervasive stigma and trauma, treatment of an asymptomatic illness with distant consequences may be a low priority (Skeer et al., 2018). In this way, the action plan to address HCV may become one of avoidance of, or nonchalance toward, treatment (Garvey & Jones, 2019). How then do veterans, who experience stigma and/or trauma, navigate these challenges to initiate treatment for HCV? Exploration among veterans who have experienced stigma and trauma, and still initiated treatment, may provide new understanding of how such individuals make decisions to promote health in the face of adversity. The following study sought to address the following research questions (RQs): RQ1: What are the illness representations concerning HCV that led to the action plan of seeking treatment? and, RQ2: In what ways are the illness representations of veterans with HCV affected by stigma or trauma?
Methods

A pilot study was first conducted to assess the feasibility of recruiting veterans at a VA health center in Eastern Massachusetts, and to assess the acceptability of the CSM and instruments to measure perceptions of HCV, stigma, and trauma in this population. Results indicated that it was not feasible to recruit a sufficiently large sample size for a cross-sectional study. Of considerable importance, the survey items were not capturing the distinction between the symptoms of HCV, and the side-effects of the medications, which at the time included Interferon and Ribavirin. Further, several veterans had stated during interviews that they wished they could speak further about their experiences beyond the scope of the surveys. Following a discussion with the author of the CSM (H. Leventhal, personal communication, July 19, 2018), it was determined that a qualitative design would be utilized to capture the complex experiences of veterans with HCV.

The following qualitative study was conducted among veterans with HCV at the VA health center in Eastern Massachusetts. All procedures were approved by the Institutional Review Boards (IRB) at the VA health center and at the first author’s academic institution.

Sample

For the current study, veterans with HCV were identified via VA medical records. Study inclusion criteria were: 1) being a U.S. military veteran over the age of 18, 2) having a diagnosis of HCV, and, 3) the most recent treatment for HCV was oral antiviral medication. This latter requirement included veterans who, at the time of screening were, a) currently undergoing oral treatment, b) had completed oral treatment, or c) had discontinued oral treatment. This also included veterans who had previously been treated with Interferon. The final inclusion criterion was, 3) the ability to speak and understand English. Exclusion criteria were: 1) diminished
capacity to provide consent or answer questions (e.g. dementia, altered mental status), 2) significant risk of harm to self or others, as noted in VA medical records, 3) treatment for HCV outside of VA, as investigators would be unable to verify treatment status, and, 4) having only been treated for HCV with an injection-based regimen like Interferon.

**Data Collection**

**Sites**

All veterans included in this study received care on-site at the HCV clinic at the VA medical center in Eastern Massachusetts. Interviews were conducted in private rooms at the VA medical center.

**Recruitment**

Veterans were recruited via procedures similar to those of a study among US veterans with PTSD and traumatic brain injury (Bayley et al., 2014). Following health record screening, recruitment letters were sent to eligible veterans. These letters explained the purpose of the study and that an investigator would contact recipients in two weeks to determine interest in participation. A phone number was provided for veterans to call or opt-out from later recruitment calls. These letters were accompanied by a cover letter signed by a VA HCV clinician, introducing the study. If no call was received by a given veteran two weeks after mailing the recruitment letter, the principal investigator (PI; first author) called the veteran to determine interest in participation and confirm eligibility. If the veteran chose to participate, a time was agreed upon for a face-to-face interview at the VA health center. Opt-out recruitment approaches have been associated with greater recruitment compared to opt-in approaches (Hunt, Schlomo, & Addington-Hall, 2013; Junghans, Feder, Heminghay, Timmis, & Jones, 2005). While the potentially sensitive subject matter of this study demanded consideration of possible distress
caused by recruitment, a study comparing opt-in and opt-out recruitment strategies among a population of bereaved relatives demonstrated no differences in level of distress between strategies (Hunt, et al., 2013).

**Interviews**

Data were collected via in-depth interviews over a ten-month period in 2019. Semi-structured interview guides were drafted to aid in exploring illness representations, stigma and trauma. Veterans were encouraged to freely express themselves with regard to their experiences with HCV. All interviews were audio-recorded for later verbatim transcription and analysis (Corbin & Strauss, 2012). Hand-written notes were also taken during and after the interview with the permission of the veteran, in order to immediately document investigator thoughts (Corbin & Strauss, 2012). Interviews were scheduled to take 1.5 hours. At the conclusion of the interview, veterans received a $50.00 gift card to CVS as compensation for their participation.

**Instruments.** Demographic data, including age, race, sex, service history, medical and mental health comorbidities, and substance use history were collected before the interview began. Substance use history was also collected at this time with the Drug and Alcohol Domains of the Addiction Severity Index – LITE (ASI-LITE). Higher scores represent greater substance use (McLellan, Cacciola, Carise, & Coyne, 1997). Cronbach’s alphas for reliability have been demonstrated to be acceptable at 0.83 and 0.81 for alcohol and drug domains respectively (Cacciola, Alterman, McLellan, Lin, & Lynch, 2007). Concurrent validity was established among patients in a methadone clinic (Cacciola, et al., 2007).

**Data and Safety Monitoring**

Veterans were advised that they may refuse to answer any question or discuss any topic and discontinue participation at any time without repercussion. Refreshments were offered over
the course of the interview, and veterans were encouraged to take breaks as needed. In the event that a veteran became distressed, and it was determined by the investigator that continued participation would be detrimental to the veteran’s wellbeing, participation would be discontinued without consent. Veterans were informed during the consent process that, at their request, VA mental health services and the Veterans Crisis Line could be made available if needed. There were no untoward reactions to the interviews.

Verbatim transcriptions of audio recordings were checked against original recordings for accuracy. Both transcriptions and original audio recordings were stored on a secured server at the VA health center. Hand-written paper notes were transcribed verbatim or scanned and stored on the same database. Paper notes from the interview, consent forms and pre-interview demographic and substance use surveys were kept in a locked cabinet. To safeguard participant identity in audio-recorded interviews, veterans were instructed to utilize a pseudonym during the interview process, which has been used in similarly sensitive research topics (Jones & Oliver, 2007). A data-use agreement outlining appropriate utilization and safeguarding of data was signed by both the VA health center and the PI’s academic institution.

Data Analysis

Data were analyzed following the method of open and axial coding as described in the grounded theory approach (Corbin & Strauss, 2012). In the present study, the CSM (Leventhal et al., 2016) served to guide analysis, interpretation, and organization of findings (Garvey & Jones, in review; Sandelowski, 1993).

Verbatim transcripts of audio-recorded interviews were read in their entirety by the PI in order to become acquainted with the material (Corbin & Strauss, 2012). The PI then conducted open coding by examining transcripts line-by-line to code excerpts within a priori categories that
had been derived from the CSM. The initial categories were: 1) Representations of Illness (Identity, Cause, Controllability, Consequences, Timeline); 2) experiences of stigma; 3) experiences of trauma; 4) experiences of diagnosis; 5) experiences of treatment; 6) the action plan to initiate treatment. Codes were compared within and across cases to create concepts within the categories (Corbin & Strauss, 2012; Miles, Huberman & Saldaña, 2020). In the method of open and axial coding, concepts are interpretations that emerge from the data (Corbin & Strauss, 2012). These concepts defined a range of experiences and perceptions among these veterans with regard to HCV (Corbin & Strauss, 2012).

Axial coding was performed alongside open coding to identify patterns among concepts (Corbin & Strauss, 2012). To mitigate the risk of biasing findings that could occur by attempting to force the data to the CSM, investigators sought to maintain a stance of uncertainty, and questioned the use of the framework throughout analyses (MacFarlane & O’Reilly-de Brún, 2012; Sandelowski, 1993; Garvey & Jones, in review). Thus, as axial coding progressed, the initial categories derived from the CSM were re-assessed for applicability to the emerging relationships between and among concepts. As axial coding progressed, concepts and codes were re-positioned between categories, initial categories were confirmed, revised, or eliminated, and new categories were formulated to fit the emerging findings. To address the research questions, these categories were ultimately refined into themes that became the 1) illness representations informing the action plan to seek treatment, and, 2) the prototypes that influenced those representations (Corbin & Strauss, 2012).

Memos were created and maintained throughout the process of analysis to explicate the concepts and relationships among concepts and to establish an audit trail (Guba & Lincoln, 1981; Miles, et al., 2020). The code book and emerging concepts were discussed with two other
investigators to aid in establishing findings (Patton, 1999): one investigator at the VA health center (third author), and one investigator at first author’s academic institution (second author). NVivo version 12 was utilized to analyze data.

**Results**

**Sample Description**

Nine veterans were recruited for this study, hereafter referred to as Veterans One through Nine (V1-V9; see Table 1). All veterans were men; one was in his late 20s, four were in their 50s, three were in their 60s, and one was in his late 70s. Seven veterans were white; two were Black or African American. Four had participated in the pilot phase of the research and had returned to conduct the in-depth interviews. Eight of the nine veterans reported a history of substance use. Six veterans indicated previous injection drug use. Two of the eight endorsed smoking or intranasal cocaine use only. Five of the nine veterans reported having a mental health diagnosis. Two veterans reported PTSD with comorbid depression and anxiety, one veteran reported comorbid PTSD and anxiety only, one veteran reported comorbid depression and anxiety only, and one veteran reported anxiety only. Of note, Veteran One was the only veteran who reported previous combat experience.

One veteran stated he was diagnosed with HCV in the late 1980s. Three were diagnosed between 1990 and 2000. Four were diagnosed after 2010. One veteran did not recall when he was diagnosed. None of the veterans in this study reported being aware of ever having developed cirrhosis or hepatocellular carcinoma in the years following their diagnosis. Four reported attempting treatment previously with Interferon. Seven had completed oral treatment at the time of the interview; one was still in treatment, and one had discontinued oral medications due to side-effects and was undergoing follow-up for HCV with his clinician.
Eight veterans were diagnosed with HCV via a positive blood test. Four were tested during substance use recovery programs. Two received testing as a part of otherwise routine care. The remaining two veterans received their diagnosis following an accident: one following a needlestick injury, and another following a traffic accident that resulted in hospitalization. Of note: one veteran was diagnosed with HCV in the 1980s, after he had experienced jaundice and vomiting. He had also reported a history of injection drug use (see Table 1).

**RQ1: Representations of HCV Informing an Action Plan to Seek Treatment**

The illness representations of consequences and controllability emerged as particularly relevant themes with regard to the development of an action plan to initiate treatment. Veterans’ representations of cause also proved important to later prototype development. The following sections elaborate these findings.

*Like Adding Sand to your Pocket: A Representation of Silent but Serious Consequences*

Seven of the nine veterans either experienced no symptoms, or very vague symptoms. The only definitive indicator of infection for eight of the veterans was a positive blood test: “I didn’t know I had it. They were just doing other…lab work and they told me…that I had Hep C” (V1). Three veterans noted vague symptoms, like fatigue or abdominal discomfort, but could not always attribute it to HCV. As one explained: “I was probably drained of energy more than I normally would have been, but how would I know? Because it’s an insipid thing that takes time” (V5). Two veterans did note acute hepatitis symptoms in early stages of infection but did not experience later symptoms of chronic infection. “I mean, after a week or so later…I was back to the same old me” (V2). Sentiments such as these were indicative of a representation of identity of an illness that was largely asymptomatic.
Of importance, despite the absence of symptoms, there was a general understanding of the threat posed by HCV, that it is a chronic infection that can result in liver damage or possibly death: “…it’s a silent killer…it can come at any time” (V2). A second veteran offered an analogy “…if every day someone’s putting a grain of sand in your pocket, you don’t notice it. Now your pockets weigh ten pounds apiece…” (V5). Sometimes, these representations arose from discussion with clinicians: “…he put it very well for a guy like me. Which is your liver’s like a sponge that filters your blood...(HCV) is like pouring paint over the sponge and letting it harden, then nothing gets filtered. And you wind up kind of getting poisoned and getting cancer” (V5). Representations of consequences also came from investigations undertaken by the veteran: “… I read in a magazine or see a picture in a magazine about a guy with cirrhosis liver…and you know, it didn’t look too pretty” (V4). These and similar views constituted representations of consequences.

The veterans in this study exhibited varying degrees of urgency, which was reflected in the representation of timeline. Among most veterans in this study, HCV was understood to be a chronic, long-lasting illness: “…it can stay in your body for years before it, it will activate itself, or something activates it” (V2). Another veteran related a similar experience: “...(my clinician) told me that…your liver functions are fine…But there’s this hidden risk. I mean, over a period of time, you could develop cirrhosis, and you can develop liver cancer…” (V6). Two Veterans, however, were more concerned about how soon symptoms would manifest, reflecting greater urgency in the representation of timeline. One, for example, pondered: “…how long does it take for that stuff to actually kick in and take your life?” (V7). Another, meanwhile, viewed HCV as a more urgent threat than HIV. This view may have reflected greater urgency in the representation of timeline.
The decision to initiate treatment was based in large part on the representation of illness consequences, and the desire to avoid outcomes that included liver disease and death. “…it’s a positive thing towards my health to get rid (my HCV infection), so it doesn’t…kill me, you know?” (V8). The representation of illness consequences was unaffected by the representation of identity that held that HCV was asymptomatic. However, the urgency of addressing potential consequences was modified depending on whether the representation of timeline reflected a more chronic course, or a more rapid or unpredictable course. For example, one veteran “…had a needle biopsy done, so I know that there was no…damage to my liver. So, I knew that I was probably able to wait for whatever cure was coming…” (V3). Conversely, another veteran wished to get treated sooner rather than later, elaborating: “I know we’ve all got an expiration date. I don’t wanna accelerate that date, you know?” (V7).

**Treatment is a Piece of Cake: A Hopeful Representation of Controllability**

The veterans in this study considered HCV to be treatable through oral medications, based on varying experiences. Some veterans noted discussions with clinicians as having encouraged treatment: “They (the clinicians) made me understand that it could be done” (V1). A second veteran noted his clinician’s “deskside manner”, which encouraged him that the oral medications would be effective: “…I felt encouraged that it wasn’t doom and gloom…he wasn’t indecisive, I guess” (V9).

Two veterans also conferred with peers regarding oral medications: “I had people that I knew and trusted that had done the same thing that I had done, and lived the life that I had lived…and I got more reference from them than I would from, you know, someone trying to push their program” (V2). Four veterans also related learning about the new oral medications through the media. One noted the banners hung around the VA, advertising the new medications:
“...once they, like, started putting out the banners in the VA, I mean...finally they got a cure. And, of course I sought after it as best I could” (V7). Another recalled learning of the oral medications television advertisements in convincing him to get treated: “I mean there was a commercial I saw on TV...that was my generation...” (V2). In these cases, outreach to veterans directly via in-house announcements or via appeal to one’s unique group may have motivated treatment.

Oral regimens were understood to be relatively short, ranging from one to three months. One veteran, who had previously taken Interferon, related: “...I can deal with being sick for two or three months after what I’ve already gone through” (V1). That said, the current oral medications were also understood to present with few side-effects, if any: “...I talked to my primary physician. She said that the side-effects were very, very minimal. Muscle aches, and maybe a little nausea...fatigue. And I thought that those symptoms were worth going through if it was going to cure my Hepatitis C” (V6). Lastly, the side-effects of oral medications were frequently contrasted with those of Interferon, which at times encouraged treatment initiation: “…(my friends) were telling me that...it’s not like the old one (Interferon)...it’s not like that. So, I went and did it” (V2). This is emblematic of the rapidly evolving representation of HCV treatment due to new generation of DAAs. Today, HCV treatment was viewed by some, in the words of Veteran Nine, as “…a piece of cake” (V9). Alongside the representation of consequences as detailed above, the understanding of the effectiveness of current oral medication, combined with the regimens perceived short length and mild side-effects, informed the action plan to initiate treatment.
How is this Possible?: Exploring the Representation of Cause

The veterans held various beliefs as to what resulted in their HCV infection, forming representations of cause. Of nine veterans, eight had a history of substance use. Four veterans believed they were exposed to HCV by injection drug use. One veteran related: “The most common way is through…IV injection of drugs and sharing needles…I acquired it through that” (V6). This veteran also related that he was “not a bit surprised” that he had HCV, given this history. Another, meanwhile, related the experience of expecting to one day get HCV while he was continuing to inject. “Yeah, I kinda figured that I would have it, because I was sharing needles …So I kinda was preparing myself for it…” (V8).

Two other veterans acknowledged a history of injection drug use but attributed their HCV exposure to other routes. Veteran One, for example, insisted he never shared needles, which required deeper exploration of his representation of cause. “…how was this possible?” he asked himself. He ultimately believed that he was exposed to HCV through sexual intercourse with women from a country where his particular genotype of HCV, GT4, was common. “So, to me it made sense, you know?” Similarly, Veteran Seven acknowledged previous injection drug use, but instead believed exposure resulted from an accident, subsequent surgery, or blood transfusion. He acknowledged that blood products would have been screened, but still attributed his transmission to the accident, given the timing of events. He stated, “I wasn’t using when this…when all of a sudden it showed up…the VA’s never seen it, like…pre-that accident.”

Two veterans acknowledged no previous injection drug use and attributed their HCV exposure to other means. Veteran Four expressed confusion at his diagnosis. His representation of cause was formulated with the assistance of his clinician: “…when I used to smoke cocaine, I used to share a stem with other people…the doctor said that…if I shared a stem with somebody
AN EXPLORATION OF THE INFLUENCE OF STIGMA AND TRAUMA

that had sores on their lips…that’s how I most likely contracted it.” Conversely, Veteran Five felt that he had multiple possible exposures in his past, in addition to intranasal cocaine use: “I took two units of blood when my hand got blown up in the Army…Or it could be from the lifestyle I had…I have tattoos.”

Finally, Veteran Three denied previous substance use, with injection drugs or otherwise. He stated that it was, ultimately, “impossible” to identify an exact cause of his HCV. However, he suspected it resulted when he accidentally ingested blood following a prank.

**RQ2: The Effects of Stigma and Trauma on Illness Representations**

Prototypes that incorporated stigma and/or trauma, had varying effects on veterans’ interpretations of illness representations. Some of these prototypes had the potential to negatively affect perceptions of controllability or minimize the consequences of HCV. These had the potential to dissuade treatment initiation. Other prototypes reframed stigma and/or trauma experiences to encourage treatment. Of importance, the prototypes that emerged were closely tied to those causes that the veterans believed resulted in their HCV infection. Substance use emerged as particularly relevant to stigma and trauma among some veterans. The following section elaborates upon the illness prototypes that emerged from analyses, and how these constructs related to illness representations.

**Stigma: Experiences and Prototypes**

All but two veterans experienced stigma related to HCV, HCV-related substance use, or HIV. Three veterans reported stigmatizing experiences directed by others with regards to substance use. Veteran Two, for example, related a story about visiting a restaurant with his relatives shortly after leaving a residential substance use recovery program: “(My nephew) reached over and took a sip out of my straw…my brother…grabbed the straw out and he said,
‘Don’t do that, you don’t know where your uncle’s been.’” He also perceived dismissal from some VA staff, particularly in relation to the substance use recovery program there. He elaborated: “You feel like a number every time you go in. Basically, pushed down the chute before you even get a chance.” In these cases, the stigma related to substance use completely supplanted the potential stigma of HCV. Another veteran who similarly contended with substance use, explained this succinctly: “…you can see active addiction easier than you see Hep C” (V9).

Four of nine veterans related varying degrees of self-blame, pointing to antecedent behaviors that they believed had led to HCV infection. One such veteran blamed himself for contracting HCV via smoking cocaine, seeing his diagnosis as a reminder of “poor decisions” (V4). Another similarly directed ire toward himself: “…fucking dummy, why were you sharing needles…” (V9). Veteran Three, meanwhile, related that “…I contracted (HCV) through stupidity.” He would later feel guilty about potentially transmitting HCV to others, both as a result of perpetrating the same prank he was a victim of, and later donating blood, unaware of his infection. “…I’m responsible for an awful lot.”, he would later say.

Five veterans spoke about stigma surrounding transmission fears. One pondered how someone would react should he or she learn of his HCV infection diagnosis: “You don’t know if, you know, if I breathe on you you’ll get it, or if I look at you too hard, you’ll get it” (V4). Such fears may be reinforced by witnessing transmission-related stigma interactions. Veteran Eight, for example, overheard peers demeaning others that were diagnosed with HCV. “…they have Hepatitis C, you know, stay away from them’…it’s definitely happened to other people.” He later wondered: “Like…is that what they would say about me, if I wasn’t around?” Veteran Five, meanwhile, referred to his fears of transmitting HCV to his family explicitly as a stigma: “The
(stigma) I did have, if you can call it that…I’m a guy, we bleed sometimes. Very aware, when I was bleeding that I could injure my family.” This may have been exacerbated by his uncertainty about what he knew or did not know about transmission risk: “I wasn’t that educated, honestly. Like, I don’t remember anybody telling me how long Hep C could live on this table, or anything like that” (V5).

Lastly, Veteran Eight related living with a dual diagnosis of HCV and HIV. He did not believe he experienced an HCV-related stigma directly, particularly given he only very recently was diagnosed with the illness. However, he recalled experiencing HIV-related stigma: “…people are…uneducated out there. If you tell them you have (HIV) then they’ll just ignore you…or look down upon you. And look at you different” (V8). This experience led to an assumption that he may have been treated similarly should he reveal he had HCV. “If they don’t know me very well, then of course they’re probably talking shit behind my back.”

Prototypes of stigma and substance use. Experienced and internalized stigma may become incorporated in a veteran’s prototype in varying ways, depending on one’s reaction and conceptualization to the stigma. The following themes emerged as prototypes related to stigma.

Keeping to myself: Limiting disclosure of HCV. In varying degrees, eight veterans preferred to keep their diagnosis to themselves, or otherwise keep to themselves. On one end of the spectrum, four veterans related a desire to keep knowledge of their HCV diagnosis on a need-to-know basis: “I don’t think the fella that sells the newspaper needs to know.” (V3) That said, there was no need to keep one’s diagnosis actively hidden, as another veteran explained: “…if someone asks…there’s no need not to tell.” (V9). Such individuals may acknowledge that HCV is a stigmatizing illness and thus keep his diagnosis private: “I guess the possibility (of stigma)…is one of the reasons why I wouldn’t go around sharing it with everybody.” (V6).
Going further, two veterans related keeping their HCV diagnosis a guarded secret. One veteran, for example, “…didn’t tell anybody. Once I found out…I didn’t tell anybody. Again, because of the stigma” (V4). For him, it was possible that the desire to keep his diagnosis a secret extended into the clinical setting. He explained further: “…I was, like, kind of hesitant and skeptical in the beginning (to work with clinicians), you know, because I figured that they would look down on me because I had this. And how I contracted it.” Another veteran, meanwhile, avoided disclosing to friends and loved ones for fear of losing relationships. For a time, this prohibited him from obtaining the stable housing required to initiate oral treatment. He explained that the clinicians believed that: “…if you leave (the medication) outside, if I was homeless, it would destroy the medication.” He could’ve lived with a friend, and thus obtained treatment, but in order to do so he needed to disclose his HCV positive status to that friend.

Lastly, two veterans related a desire or willingness to disconnect from others who would stigmatize them. One, speaking of people who stigmatized his peers, related: “…it…made me not want to be around that person, or…hang around that person.” (V8). He further stated a willingness to confront such individuals, stating: “…I tell them that, you know, everybody has their problems…it’s not affecting you…don’t talk (expletive) to them.” (V8). Veteran Two, meanwhile, referred to himself as a “loner”. Following the incident in the restaurant, he cut off all contact with his family until recently. He explained: “What I do is who I am. If you can’t take me for that, then I guess there’s no you and I.” (V2). To that point, he also expressed a desire to disengage from the VA, citing a perceived lack of regard from the institution and staff. This tactic may have extended into the clinical setting. Veteran Two recalled a conversation he had with a clinician, whom he perceived as being dismissive of his care needs: “I said who are you servicing? You, or the veteran? And she walked away all pissy and disgusted…and you wonder
why I don’t want to come through here anymore?” Veterans whose experiences are incorporated into a prototype such as this, may be discouraged from seeking treatment to protect against judgement or dismissal.

*Welcome to the party!: Learning how to accept a diagnosis of HCV.* Understandably, because inclusion criteria required treatment initiation, all veterans in this study ultimately chose to initiate treatment for HCV. Stigma was addressed in various ways. Three veterans were encouraged by clinicians’ acceptance of persons with HCV. Veteran Four, for example, spoke of his clinician: “…they said they’re here to help. And you know…they can’t help me unless I tell them what’s wrong with me.”. He trusted that his clinician was a professional who was “bounded by confidentiality” (V4). Another veteran echoed this, saying that clinicians would try to make interactions “…as positive as possible” (V7), regardless of how they may have felt privately.

Veteran Two, meanwhile, elected to initiate HCV treatment after encountering a clinician who didn’t make him feel “like a number”, and “…was very adept at telling me every side-effect and everything that possibly could happen.” These individuals may have still possessed lingering stigma. It was the experience of acceptance, contrary to expectations of rejection, that resulted in a prototype that enabled the continuing interaction with clinicians and others required to obtain treatment.

Veterans also related positive perceptions and interactions with peers as well. Veteran Seven, for example, remarked how positive the reaction was when he disclosed to his friend: “…I gained a lot of trust with her once I kind of leveled with her…” He was subsequently able to obtain housing with her and initiate oral treatment. Veteran Four, meanwhile, continued to keep his HCV diagnosis a secret outside the clinical setting. He wondered, however, whether his peers would actually hold HCV against him: “…my circle at the time, they could care less. Because
they, most likely, they had other diseases themselves…that was like, well, welcome to the
d party!” Another veteran echoed this sentiment: “…most vets that I know of are in residential
housing…they all have some sorta physical and mental…conditions going on…they got other
things to be concerned about. Believe me” (V1). In cases like these, the perception of the issues
faced by one’s peer group may have ameliorated fears related to stigma.

Going further, three veterans took a dismissive stance on stigma: “…Why would I worry
about a stranger knowing that I had Hep C?” (V6). Another remarked: “You know, they can talk
and do whatever in the peanut gallery. It doesn’t affect me.” (V5). Another still went further:
“…you’re gonna have to get up pretty early in the morning to offend me…if you want to be
politically incorrect, knock yourself out, I’d enjoy it!” (V9). That said, some of these veterans
recognized the potentially harmful effects stigma can have on others, if not themselves: “If
they’re judging me, it’s keeping them off of someone that can’t take it.” (V5). Such sentiments
may reflect an attitude that stigma is recognized but not internalized.

Lastly, Veteran Eight expressed a willingness to disclose his HCV status, regardless of
past experiences of stigma with HIV. “…living with both of them is difficult.” He elaborated:
“Especially trying to find a sexual partner…I always tell them anyways…cause it’s just
respectful, you know?” In this veteran’s case, feelings around stigma may have persisted, but the
view of disclosure as being a “respectful” behavior may have negated hesitancy surrounding
discussion of his illness, enabling treatment initiation.

I can mess up someone else’s life: Fears regarding transmission. Three veterans held
strong feelings related to the risk of transmitting HCV to others. Veteran Three, as discussed
previously, experienced considerable guilt related to possibly transmitting HCV to others in the
past. Prior to initiating oral treatment, he took steps to safeguard his family against accidental
transmission, to the point of being “hypervigilant”, in his words. Even after having completed treatment, his guilt persists. He described having watched commercials for HCV treatment, wondering whether or not he infected any of the people featured in the advertisement.

Another veteran feared “messing up someone else’s life” (V4), by transmitting HCV. This was coupled with his fear of how other would react should they learn of his illness: “I’m thinking that if I told you I had Hepatitis C, you may not want to stay in this room with me…Because maybe you don’t know about it” (V4). This was exacerbated by his own lack of education about HCV: “…didn’t know about it either. I didn’t know if I…breathed on you, you could get it” (V4). A third veteran, acutely aware of the possible risk to his family, related feeling “clean” (V5) after completing oral HCV treatment.

In these cases, accurate understanding of the risks of transmitting HCV to others may have driven an internalized stigma because of the emotional value placed on that risk, including guilt, fear, or feeling dirty. In such cases, these feelings may have encouraged HCV treatment. As one related: “The stigma…was in my mind…that was my imagination telling me how people was going to react to me…and that within itself, you know, encouraged me to get treated.” (V4). A second stated: “…to know that I could…bleed on something and not infect my family, that was cool.” (V5).

**Trauma and Substance Use**

Three veterans noted they had been diagnosed with PTSD on the demographic survey. All by one veteran had a history of substance use. One such veteran connected trauma exposure and substance use. He disclosed that he had been sexually assaulted in the military, and eventually began injecting drug to cope with his response to that trauma. He elaborated: “…the pain and the embarrassment and the shame of (the assault) led to more drinking. And then I
found out there were other substances that were quicker” (V9). A second veteran similarly used injection drugs to alleviate grief following the loss of two family members in rapid succession. He would later explicitly describe the day-to-day experience of addiction, including exchanging sex, as traumatic. Veteran Two, meanwhile, did not endorse any one event that may have resulted in his diagnosis, but noted a near-fatal, multi-week binge: “…you cannot imagine what being alone for six weeks in a motel …just consuming alcohol and cocaine the whole time…when they found me…I was seventy-eight pounds, soaking wet.”

Five veterans described potentially traumatic experiences, but did not indicate they had PTSD. Veteran One, for example, related experiences in gang environments and war. “I had been a fighter since I was eight years old…one extreme to the next…you go from using your fists to using knives, eventually using pistols.” Veteran Five, meanwhile, described a service-related injury: “…the mix of alcohol and explosives is not a good one, and I hurt myself…I required two units of blood.” (V5). Veteran Seven had been in a motor vehicle accident. He described the night he was struck by a car: “…I was crossing the street…the man driving kinda swerved into that median…I saw the headlights, and the headlights became a blur, and the next thing I was waking up in an ambulance.”

Trauma, substance use, and HCV. Trauma and/or substance use were connected to HCV in various ways. Two veterans viewed their injuries as contributing to their HCV exposure. “…it’s scary…you can go into a hospital and get an operation…somewhere in the procedure of me getting cut open…actually being friggin’ struck down by a motor vehicle” (V7). Two veterans saw their trauma experience as being indirectly related to their HCV exposure, by way of injection drug use. As one elaborated: “…having the PTSD and the depression, anxiety, in order to deal with that I gotta use drugs. And then drugs, with drugs come sex, and sharing
needles and all that. And that led it into getting the Hep C” (V8). Veteran Two, meanwhile, related a tortuous trajectory of HCV diagnosis, substance use, and eventual drug treatment. Even after coming down with acute symptoms of HCV, he continued injecting drugs: “…it did not scare me, because my drug use was just too strong.” He believed one of his friends whom he injected with had exposed him to HCV. As a means to protect himself from further exposure, he gradually isolated from his friends. This culminated in the cocaine and alcohol binge that nearly took his life. He entered long-term substance use recovery following these events.

**Prototypes of trauma and substance use.** As with stigma, the experience of trauma may become incorporated into a veteran’s prototype, thus influencing action planning with regard to HCV. The following prototypes of trauma and substance use emerged from these analyses as themes.

**In the grips of trauma and addiction: Minimized consequences.** Four veterans previously minimized the potential consequences of HCV. The strength of one’s addiction, and the need to get high, was noted by three. One noted he was unconcerned about HCV: “’Cause I was…in the grips of drug addiction. Alcoholism. It just…you can’t scare an addict straight.” (V9) Another related that he “…really didn’t care about nothing but the next high, or didn’t even care if I died, really.” (V8).

Veteran One, meanwhile, expressed hesitancy in initiating treatment for his HCV, pointing to the lack of symptoms of his infection, and the lessons he learned from past adversity. Life in war and in gang environments taught him “if there wasn’t something immediately affecting your health…you didn’t give it much thought.”. Today, as a man in his 70s, he saw himself living on “borrowed time”. He said, “…I was very nonchalant about whether I got
treatment or not.”. Numbness that may have been an extension of past trauma, coupled with an illness that “didn’t hurt”, could have rendered the consequences posed by HCV to be moot.

In the rear-view mirror: Leaving trauma and substance use behind. As with stigma, all the veterans in this study who experienced trauma eventually came to frame these experiences in such a way that led them toward HCV treatment. The veterans in this study emphasized the need to move forward with treatment and leave behind pasts that included trauma and/or related substance use. Speaking of his self-inflicted injury and substance use, which may have led to his HCV exposure, one veteran related that his “life philosophy is that there is a darn good reason why the windshield is so much bigger than the rear-view mirror. Because what’s important is in front of you, not behind you” (V5). Having moved on from his past substance use and self-inflicted injury, he would go on to make multiple attempts at treating his HCV, stating “…I never feared Hep C, because I always knew I was twice as tough as Hep C.” Another veteran offered a similar view: “You can only go forward. I’m drug free. I’m remaining drug free…” (V6). Upon learning of his HCV-positive status, the decision whether to initiate treatment was clear: “Better deal with it now, if I don’t want it to get to (cirrhosis or liver cancer)” (V6).

Two veterans related key life events that resulted in pursuit of trauma and substance use recovery, and ultimately HCV treatment. Veteran Nine experienced a car crash while under the influence of alcohol. Having described himself during the interview as his own “hardest critic”, he decided it “…time to face the world again.” He spoke of his girlfriend, and in-part sought HCV treatment for her sake: “…I would like to spend as much time as I can with her…” Treatment of his HCV was viewed as a logical next step: “…the opportunity’s here for some reason. Take it. While I can.” A second veteran related the experience of overdosing in front of his mother: “…I just needed to get help for her, and for myself…family is what helped me.”
(V8). Upon entering long-term substance use recovery, he related a newfound caring for his own wellbeing, and a desire to spend to move forward toward a “successful life” (V8). Part of these efforts included HCV treatment. In the case of these two veterans, HCV treatment may have become something to pursue for the sake of one’s own health, and for the sake of loved ones.

For Veteran One, who initially dismissed HCV as non-threatening as a man living on “borrowed time”, treatment occurred thanks to the consistent efforts of his clinicians. As he said, “Had it have been a weaker person…that really didn’t show that kind of intense interest, I probably wouldn’t have done it.” This veteran’s interactions with his clinicians revised his prototype, wherein treatment was viewed as worthwhile for the sake of his own wellbeing, as well as the happiness of others. “If these (clinicians) were so convinced that it would be a benefit for me, it was almost like I was, um, doing it because they wanted me so much to do it.” Today, HCV is now “…one thing I wouldn’t have to carry.”

**I’m not stable yet: Prioritizing substance use recovery over HCV.** Importantly, some veterans in this study who were in the process of moving forward following trauma and substance use still avoided treatment. For two veterans, other priorities may have competed with HCV treatment. This may have resulted in a prototype that is very similar to “in the rear-view mirror” but sees HCV as a lower priority.

Following his near-fatal binge, Veteran Two entered into substance use recovery, pouring himself into his job. Later, when Interferon arrived as a treatment option, he refused, fearing he would lose his job as a result side effects. He elaborated: “…I don’t want to go back to no homeless situation…That’s what I looked at with the old program that y’all have with Hep C.” This veteran’s prototype held that whatever risks of consequences were posed by HCV were
outweighed by the risk of a return to substance use and homelessness posed by injections with Interferon.

Veteran Four, meanwhile, viewed his past substance use as shameful. He elaborated: “…when I first came (into drug recovery)…everything was, like, overwhelming for me…’cause of the destruction I caused.” He spent time in denial of his diagnosis, pointing to his lack of injection drug use: “The doctors don’t know what they’re talking about.” In time, after multiple positive tests, he came to accept his diagnosis, and took a brief round of Interferon to put the infection “into remission” in his words. He did not seek full treatment, however, stating he was not yet “stable” enough to do so. Thus, he “…completely blocked it out of my mind…hoping that it would go away.”

For these two, the introduction of DAAs, and an attendant change in the representation of controllability, may have permitted treatment with ongoing recovery. Veteran Two was still skeptical, but discussion with his clinician and his peers convinced him that he would be able to continue working while taking DAAs, thus maintaining his ongoing recovery. Meanwhile, Veteran Four expressed hope upon learning of new “cure” from clinicians and commercials, effectively shaking loose the mental block that prevented him from thinking of HCV. He said, “…once I found out that there was a cure for it, it didn’t take me no time to decide to do it.” He came to view HCV treatment as something to be proud of: “…another thing that…I was able to accomplish…for once I got back into recovery.”

Discussion

This study explored the perceptions of HCV, as well as experiences of stigma and trauma among nine veterans who had initiated oral treatment for HCV. The first research question (RQ1) asked what are the illness representations concerning HCV that led to the action plan of
seeking treatment? Addressing this question: the action plan to initiate oral treatment for HCV among veterans was informed by a, 1) representation of HCV as possessing severe and possibly fatal consequences, and, 2) a representation that HCV was controllable through oral medication. The common perception of veterans in this study held that HCV was, 1) asymptomatic, but, 2) potentially life-threatening. The course of illness was largely perceived as 3) chronic, but some veterans held the belief that HCV followed a more rapid or unpredictable course of illness. These views constituted representations of illness, 1) identity, 2) consequences, and, 3) timeline, respectively. In terms of treatment, the common perception of veterans in this study held that oral medications would be effective in treating HCV. This was enhanced by perceptions that oral medications were, 1) relatively quick-acting, and, 2) presented with minimal side-effects. These perceptions were encompassed under representations of, 1) treatment timeline, and, 2) treatment identity, respectively. These findings are similar to findings from recent research of DAA completion among veterans (Skolnik et al., 2019), and positively reinforce the role of providing effective education to patients concerning consequences of HCV and available treatment options (North et al., 2013).

The second research question (RQ2) was more complex, asking in what ways are the illness representations of veterans with HCV affected by stigma or trauma? Importantly, these prototypes concerning stigma and trauma influenced the interpretation of illness representations to encourage or discourage treatment initiation. In terms of the CSM, the prototypes incorporating stigma and trauma either, 1) matched, or, 2) mismatched to the representations outlined in RQ1 to support or not support the action plan to undergo treatment respectively (see Table 2).
When there was a mismatch between the representations discussed in RQ1, and the veterans’ prototype of HCV, an action plan to initiate HCV treatment was not supported. For example, the representation of consequences, “like adding sand to your pocket”, shows recognition of the long-term health risks of HCV, despite the gradual and potentially painless course of infection. This recognition provided an impetus for treatment. The prototype, “in the grips of trauma and addiction”, however, may have minimized the sequelae of HCV compared to the struggle with addiction or trauma. In this case, there was a mismatch between the representation and the prototype.

Conversely, when veterans’ prototypes of HCV matched to representations of consequences or controllability, an action plan to initiate treatment was supported. The prototype “in the rear-view mirror” placed prior trauma and substance use in the past. This prototype did not minimize the long-term health risks of HCV and was more likely to be matched to a representation of consequences such as, “like adding sand to your pocket”. This match, in turn, encouraged the decision to initiate treatment for HCV.

Some veterans apparently held a matching prototype from the outset. For others the prototype changed over time. Those veterans “in the grips of trauma and/or addiction”, may have viewed the sequelae of HCV as inconsequential. This represented a mismatch between the prototype and the representation of consequences, “like adding sand to your pocket”. In time, however, these veterans sought to place such events “in the rear-view mirror”: moving forward from trauma and substance use. In this case, the prototype came to match the representations of consequences, with sequelae that are worth averting. Other veterans were similarly hesitant to discuss HCV for fear of stigma, in effect “keeping to themselves.” If receipt of DAAs was somehow predicated upon discussion about HCV, be it with a clinician, or a family member or
another figure, then this prototype may have interfered with treatment initiation. This prototype may thus be seen a mismatch to the representation of controllability as being “a piece of cake”. One veteran who possessed such a prototype, however, eventually came to the conclusion that clinicians were professionals who sought to help him, regardless of his past. In effect, he was “welcomed to the party”. His previous prototype incorporating stigma was superseded by one that emphasized acceptance and enabled treatment, matching to the representation of controllability, thereby encouraging treatment.

Two prototypes uncovered in these analyses matched with representations of HCV in ways dissimilar to the above examples. First, the prototype of stigma, “I can mess up someone else’s life”, as discussed earlier, may resonate with representations that define HCV as consequential. In this case, the veteran may wish to avoid transmitting HCV to others, especially if he is aware of the long-term sequelae of HCV. Second, some veterans who had been trying to put things “in the rear-view mirror” were also “not stable yet” and prioritized other important matters, such as continued substance use recovery, over HCV treatment. This prototype may match to the representation of controllability that HCV treatment is a “piece of cake”. The veteran may still not yet be “stable”, perhaps contending with continuing drug recovery, but tolerable and effective oral medications enable treatment in spite of these challenges.

Several of the findings in this study are consistent with existing literature with regard to HCV treatment in veterans. These included perceptions of side-effects (Phillips & Barnes, 2016b; Zuchowski et al., 2015), the importance of helpful patient-provider relationship (Rogal et al., 2016), and the desire to be cured of a chronic and potentially fatal illness (Clark & Gifford, 2015; Phillips & Barnes, 2016a). These studies, however, were largely conducted during the period when HCV was treated with Interferon, which was characterized by difficult side-effects
compared to current DAAs (Kwo et al., 2017; McHutchinson et al., 2009). Another important distinction for the current study was a focused exploration of the decision to initiate treatment, as opposed to continuing adherence or treatment completion. A recent qualitative study suggested that a positive patient-provider relationship, along with a perception that current medications will effectively cure a potentially fatal illness, motivated veterans to complete DAA treatment (Skolnik et al., 2019). However, treatment initiation and treatment completion are distinct phenomena. For example: whereas adherence or completion may be dependent upon medication side-effects experienced in the present (Phillips & Barnes, 2016a), treatment initiation may be dependent upon anticipated side-effects (Zuchowski et al., 2015). Given the relatively recent introduction of DAAs following the use of Interferon, attention to veterans’ prototypes and representations of illness, ahead of treatment, may suggest future research concerning treatment for veterans who have not accessed treatment.

To the authors’ knowledge, the present study is the first to explore stigma, trauma, substance use and illness representations as a part of a theoretical framework to explain how veterans decide to initiate HCV treatment. Minimizing the long-term sequelae of HCV, perhaps owing to the interfering symptoms of trauma or substance use, and discouragement owed to a fear of stigma, were prototypes that presented a challenge to treatment seeking. Meeting veterans where they are in terms of mental and emotional health may be beneficial in encouraging HCV treatment. Suggestive of this benefit, one randomized-controlled trial of veterans during the period of treatment by Interferon, indicated that integrating mental health and substance use recovery concurrent with HCV treatment demonstrated increased treatment initiation rates (Ho et al., 2015). The veterans in the present study also emphasized moving past trauma and substance use to focus on accessing care. The role of moving on from one’s past been similarly noted in
previous research among both veterans (Clark & Gifford, 2015; Phillips & Barnes, 2016a) and non-veterans (Williams, et al., 2019). Current oral medication regimens may allow for more flexible HCV treatment for those veterans who may be in the midst of recovery from trauma or substance use or both. The findings of this study reinforce the need to address trauma and substance use in HCV treatment.

The present findings also contribute to the literature concerning the role of an accepting and non-judgmental environment in the clinical setting (Rogal et al., 2016; Skolnik et al., 2019). Veterans in the current study emphasized the importance of respectful treatment. Conscientious attempts to defeat HCV-related stigma in the setting may encourage veterans to discuss relevant but sensitive topics to clinicians or others, thereby facilitating treatment decision-making. This may particularly be the case if multiple clinic visits are required before prescription of DAAs may be received. This may also be the case if a veteran relies upon his or her family and friends for social support (Phillips & Barnes, 2016b).

Of note, however, several veterans in this study related that they had perceived relatively little stigma regarding HCV directly. Instead, they noted that the stigma they had experienced was due to their substance use or co-morbid HIV. This finding suggests that addressing stigma among persons with HCV requires an exploration of the ways a veteran may feel stigmatized. For instance, recent research has suggested that persons with both HCV and HIV experience stigma differently based upon gender, race, education, income, and treatment status, compared to those only with HCV (Saine et al., in press). Some veterans in this study also relating feeling hypervigilant and guilty when thinking of HCV transmission risk, which has been also reported among non-veterans (Williams et al., 2019). A holistic approach to addressing stigma (Saine et
al., in press), accounting for personal history, demographics, comorbidities and transmission risk may thus be beneficial.

Lastly, while not explicitly addressed by the research questions, the experience of substance use emerged as particularly important to the formation of prototypes of stigma and trauma. This is perhaps not surprising, given eight of the nine veterans reported a history of substance use, with six describing injection drug use. The experiences of substance use often became intertwined with that of trauma. This is understandable, given the relatively high comorbidity of substance use among veterans with PTSD (Wisco et al., 2014). This is also understood by the role that substance use can play in numbing the symptoms of a post-traumatic response (Haller & Chassin, 2014). Further, some discussed stigma in relation to their substance use history, a connection that has been described previously in relation to HCV (Dowsett et al., 2017). The findings of the present study suggest further research concerning stigma, trauma, and substance use in regard to treatment initiation.

**Study Limitations**

Limitations of the study findings include the small sample size and the fact that the study took place at a single VA health center in Eastern Massachusetts. However, consistent with the qualitative paradigm, the goal of this exploration was not to produce findings that are generalizable to a wider population, but rather to provide a context-laden picture of a given phenomenon (Guba & Lincoln, 1982). With this in mind, the authors believe that the richness of data obtained in the nine interviews was sufficient to tell a cohesive story (Corbin & Strauss, 2012; Morse, 2015; Sandelowski, 1995) about how a group of veterans chose to get treated for HCV. The authors further believe analyses achieved “code saturation” or “thematic saturation”, wherein the breadth of codes or thematic range for the research questions have been established
(Hennink et al., 2017). Additional interviews would have been beneficial to further explore the contingencies of the codes identified in these nine interviews, to establish a deeper “meaning saturation” (Hennink et al., 2017). The findings reported here explore the perspectives of two veterans of color. Because HCV affects Black or African Americans and Latinx veterans at a greater rate than White veterans (Backus et al., 2014), the findings would be further enriched by increased participation among Black or African and Latinx veterans. Also, despite the low prevalence of HCV among women veterans (Noska et al., 2017), exploration among women veterans is needed to understand gender differences in the experience of HCV. Future research may also benefit from increasing participation of veterans who are homeless, given their higher prevalence of HCV compared to veterans who are not homeless (Noska et al., 2017). One veteran in this study provided insights into how experiences of combat shaped his perception of HCV later in life. Future research on the effects of trauma on HCV treatment initiation may benefit from increased participation of veterans with combat experience, in order to further explore the unique experiences of this group. Further, the sample was constrained only to those veterans engaged in care in the VA system. These veterans may have had different motivations to engage in HCV care compared to veterans accessing care outside the VA. Lastly, exploration of the decision to initiate treatment explores one side of the story. Future research may consider reasons for not seeking or refusing treatment.

However, a strength of this study is in its exploration of treatment initiation through the CSM. Past qualitative studies conducted in veteran populations have broadly explored personal factors associated with HCV treatment initiation, adherence, and completion, but relatively few have attempted to explicate the role of representations of illness, and how they may be viewed through the lenses of stigma, trauma, and substance use. In the present study, the CSM provided
a framework to explore the complex factors that play into the decision to initiate treatment for this predominately asymptomatic but potentially emotionally-laden illness, at a point in time where tolerable and effective treatment is available. The findings of this study support the utilization of the CSM in this population (Garvey & Jones, 2019), and the framework may have utility in other populations whom may experience stigma and/or trauma, such as persons with HIV (Brezing, Ferrara, & Freudenreich, 2015; Chambers et al., 2015).

Conclusion

Up to 15,000 veterans in the VA remain untreated for HCV (VA, 2020a). Veterans acknowledge the potential consequences of HCV and the means to treat it with oral medication (Clark & Gifford, 2015; Phillips & Barnes, 2016a; Skolnik et al., 2019). However, exposure to stigma, trauma and substance use indicate that the decision to initiate treatment can be more complex. Veterans in this study recognized the risks of liver disease and possible death posed by HCV, forming a representation of consequences. They also understood that there were effective medications to treat HCV, forming a representation of controllability. However, for some, the HCV diagnosis unearthed feelings related to past stigma, trauma, and substance use. Each had the potential to interfere with the decision to seek antiviral treatment. Memories and emotions surrounding stigma, trauma and substance use may have constituted prototypes that were mismatched to representations of HCV controllability and consequences. However, these veterans overcame stigma, or reframed trauma and substance use in the light of ongoing recovery, forming new prototypes of HCV. These new prototypes matched the representations of controllability and consequences which had conferred the need for treatment. The CSM provided a flexible framework in this study to explore the complex decisions that veterans make regarding treatment initiation, at a point in time when tolerable and effective treatment is available. The
findings of this study have implications for further research into the care of veterans with HCV who contend with stigma, trauma, and substance use.

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**Declaration of Conflicting Interests**

The authors declare that there is no conflict of interest.
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Hepatitis C 2014. Washington, DC.


Appendix A

## Appendix B

**Table 1: Selected Characteristics of Study Participants from Pre-Interview Demographic Survey**

<table>
<thead>
<tr>
<th>Participant ID</th>
<th>Race</th>
<th>Age Group</th>
<th>Injection Drug Use History</th>
<th>Comorbid Mental Health Diagnoses*</th>
<th>Previous HCV Treatment Attempts</th>
<th>Oral HCV Treatment Completion</th>
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<td>Veteran One (V1)</td>
<td>Black/African American</td>
<td>70+</td>
<td>Yes</td>
<td>N/A</td>
<td>Yes(^1)</td>
<td>Completed</td>
</tr>
<tr>
<td>Veteran Two (V2)</td>
<td>White</td>
<td>50-60</td>
<td>Yes</td>
<td>Depression, Anxiety, PTSD</td>
<td>No</td>
<td>Discontinued</td>
</tr>
<tr>
<td>Veteran Three (V3)</td>
<td>White</td>
<td>60-70</td>
<td>No</td>
<td>Anxiety</td>
<td>Yes(^2)</td>
<td>Completed</td>
</tr>
<tr>
<td>Veteran Four (V4)</td>
<td>Black/African American</td>
<td>60-70</td>
<td>No(^a)</td>
<td>Depression, Anxiety</td>
<td>Yes(^1)</td>
<td>Completed</td>
</tr>
<tr>
<td>Veteran Five (V5)</td>
<td>White</td>
<td>50-60</td>
<td>No(^b)</td>
<td>N/A</td>
<td>Yes(^1)</td>
<td>Completed</td>
</tr>
<tr>
<td>Veteran Six (V6)</td>
<td>White</td>
<td>60-70</td>
<td>Yes</td>
<td>N/A</td>
<td>No</td>
<td>Completed</td>
</tr>
<tr>
<td>Veteran Seven (V7)</td>
<td>White</td>
<td>50-60</td>
<td>Yes</td>
<td>N/A</td>
<td>No</td>
<td>Completed</td>
</tr>
<tr>
<td>Veteran Eight (V8)</td>
<td>White</td>
<td>20-30</td>
<td>Yes</td>
<td>Depression, Anxiety, PTSD</td>
<td>No</td>
<td>Completed</td>
</tr>
<tr>
<td>Veteran Nine (V9)</td>
<td>White</td>
<td>50-60</td>
<td>Yes</td>
<td>Anxiety, PTSD</td>
<td>No</td>
<td>In-Progress</td>
</tr>
</tbody>
</table>

*Based on self-report

\(^a\)Smoking cocaine only

\(^b\)Intranasal cocaine only

\(^1\)One previous treatment attempt with Interferon

\(^2\)Two previous treatment attempt with Amantadine, then Interferon

Note: HCV = Hepatitis C Virus, N/A = not applicable, PTSD = Posttraumatic Stress Disorder
Appendix C

Table 2: Prototypes, when matched to illness representations, inform action plans to address health threats

<table>
<thead>
<tr>
<th>Illness Prototype</th>
<th>Relevant Illness Representation</th>
<th>Match Between Prototype and Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stigma: Limiting Disclosure of HCV</td>
<td>Hopeful Representation of Controllability</td>
<td>No</td>
</tr>
<tr>
<td>Stigma: Learning How to Accept a Diagnosis of HCV</td>
<td>Hopeful Representation of Controllability</td>
<td>Yes</td>
</tr>
<tr>
<td>Stigma: Fears Regarding Transmission</td>
<td>Silent but Serious Consequences</td>
<td>Yes</td>
</tr>
<tr>
<td>Trauma: Minimized Consequences</td>
<td>Silent but Serious Consequences</td>
<td>No</td>
</tr>
<tr>
<td>Trauma: Leaving Trauma and Substance Use Behind</td>
<td>Silent but Serious Consequences</td>
<td>Yes</td>
</tr>
<tr>
<td>Trauma: Prioritizing Substance use Recovery Over HCV</td>
<td>Hopeful Representation of Controllability</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Note: HCV = Hepatitis C Virus
Chapter 5: Summary

Hepatitis C Virus infection (HCV) is a blood-borne infectious disease that presents a long-term risk for cirrhosis and hepatocellular carcinoma, despite being otherwise largely asymptomatic (Centers for Disease Control and Prevention [CDC], 2020). Hepatitis C Virus (HCV) infection disproportionately affects veterans in the United States (U.S.; Hofmeister et al., 2019; Noska et al., 2017). While there are now effective oral medications to treat HCV (Kwo et al., 2017), experiences of stigma among veterans may discourage treatment initiation (Miller, McNally, Wallace, & Schlichthorst, 2012; Rogal et al., 2016). In addition, many U.S. veterans with HCV contend with trauma (U.S. Department of Veterans Affairs [VA], 2014). Symptoms of a traumatic response, including numbness, agitation and resultant avoidance, may also present challenges to seeking care (van der Kolk, 2014). The preceding dissertation explored how veterans with HCV, who also experience stigma and trauma, decide to initiate treatment.

Each of the three manuscripts in this report provided a stepping-stone toward the completion of the dissertation. The first manuscript (Chapter 2) featured a discussion that explored the Common-Sense Model (CSM: Leventhal, Phillips, & Burns, 2016) and its applicability in veterans with HCV (Garvey & Jones, 2019). The strength of the CSM as a framework is its emphasis on the process of a person detecting and interpreting health threats and then formulating responses to manage them (Leventhal et al., 2016). Within the CSM, action plans to address illness are predicated upon a match between, 1) one’s memories of a given illness, known as a prototype, and, 2) schematic perceptions of an illness, known as illness representations. This manuscript explored how stigma and trauma, incorporated into a veterans’ prototype of HCV, may interfere with the decision to initiate treatment. This exploration served to inform later analyses in the qualitative dissertation study.
The second manuscript (Chapter 3) presented an argument for the utilization of theoretical frameworks in the qualitative paradigm (Garvey & Jones, in review). Theoretical frameworks may be utilized to guide qualitative analyses by suggesting concepts and relationships among concepts to explore (Miles, Huberman & Saldaña, 2020). However, there are concerns that the use of a theoretical framework may bias findings or stifle inductive discovery (Corbin & Strauss 2012; Morse, 1992). With this in mind, it is helpful to think of a theoretical framework as a map (Miles et al., 2020), which leads to a treasure (findings) in the center of an island (data; Garvey & Jones, in review). In using the map, one must still use one’s skills and instincts to navigate the island (methodical coding, reflection, and writing; Corbin & Strauss, 2012; Morse, 1992). This manuscript explored the utilization of the CSM in the dissertation study. This discussion informed the approach to data analyses for this dissertation, with an emphasis on methodical coding, as well as thoughtful reflection of the applicability of the framework (MacFarlane & O’Reilly-de-Brún, 2012; Sandelowski, 1993).

The lessons learned from the writing of the first and second manuscripts informed approaches to analyses in the final dissertation. The third manuscript (Chapter 4), reported the findings of the dissertation study. This qualitative exploration sought to understand, in the face of stigma and trauma, how veterans decided to initiate treatment with current oral direct-acting antiviral medications (DAAs). Nine veterans were recruited for face-to-face, in-depth interviews to discuss their experiences of HCV diagnosis, perceptions of their illness, exposure to stigma or trauma, and how they decided to get treated. Data were analyzed following the method of open and axial coding as described in the grounded theory approach (Corbin & Strauss, 2012). Analyses were guided by the CSM (Leventhal et al., 2016). This study sought to address the following research questions (RQs): RQ1: What are the illness representations concerning HCV
that led to the action plan of seeking treatment?, RQ2: In what ways are the illness representations of veterans with HCV affected by stigma or trauma?

**Overview of Dissertation Study Findings**

This dissertation explored the perceptions of HCV, as well as experiences of stigma and trauma among nine veterans who had initiated oral treatment for HCV. Addressing RQ1: the action plan to initiate oral treatment for HCV among veterans was informed by, 1) representation of HCV as possessing severe and possibly fatal consequences, and, 2) a representation that HCV was controllable through oral medication. Addressing RQ2: prototypes concerning stigma and trauma influenced the interpretation of illness representations to encourage or discourage treatment initiation. These prototypes either, 1) matched, or, 2) mismatched to the representations outlined in RQ1 to support or not support the action plan to undergo treatment respectively.

When there was a mismatch between the representations discussed in RQ1, and the veterans’ prototype of HCV, an action plan to initiate HCV treatment was not supported. For example, the representation of consequences that showed recognition of the long-term health risks of HCV provided an impetus for treatment. However, some veterans possessed a prototype that minimized the sequelae of HCV compared to the struggle with addiction or trauma. In this case, there was a mismatch between the representation and the prototype. Conversely, when veterans’ prototypes of HCV matched to representations of consequences or controllability, an action plan to initiate treatment was supported. A prototype that placed prior trauma and substance use in the past and does not minimize the long-term health risks of HCV was likely to be matched to the above representation of consequences. This match, in turn, encouraged the decision to initiate treatment for HCV.
This also occurred among veterans who were hesitant to disclose HCV or interact with others due to concerns regarding stigma. If receipt of treatment was somehow predicated upon discussion about HCV, be it with a clinician, or a family member or another figure, then this prototype may have interfered with treatment initiation. This represented a mismatch to the representation of controllability that suggested HCV is treatable. Welcoming interactions and positive perceptions of clinicians, peers and family, however, instilled acceptance of HCV in veterans, and a willingness to engage with others regarding their illness. This prototype matched to the representation of controllability, thereby encouraging treatment.

**Directions for Future Nursing Research**

This dissertation adds to the body of evidence exploring how veterans contending with stigma and trauma decide to initiate treatment for HCV. Several of the findings of this dissertation are consistent with existing literature regarding HCV treatment in veterans. These included perceptions of sequelae of HCV (Clark & Gifford, 2015; Phillips & Barnes, 2016), and perceptions of the effectiveness of oral medications (Skolnik et al., 2019). For some, however, the decision to initiate treatment was discouraged by their own prototypes that incorporated stigma and trauma. Veterans in this study were able to initiate treatment for HCV through acceptance of their illness, and a reframing of past trauma and substance use to emphasize recovery concurrent with HCV treatment. These findings enrich the understanding of how veterans, contending with stigma and trauma, initiate treatment for a largely asymptomatic but potentially fatal illness. Attendance to the mental and emotional health of veterans with HCV care may be beneficial in encouraging HCV treatment (Ho et al., 2015). The present findings also contribute to the literature concerning the role of an accepting and non-judgmental environment in the clinical setting (Rogal et al., 2016; Skolnik et al., 2019).
The findings of this dissertation may inform future nursing and allied health research exploring HCV treatment initiation among veterans, and the relationships of stigma, trauma and substance use. Future research toward these ends would benefit from increased participation of Black or African American and Latinx veterans, and veterans who are homeless, given greater prevalence of HCV in these groups (Backus et al., 2014; Noska et al., 2017). Exploration among women veterans is also needed to understand gender differences in the experience of HCV. Lastly, future research may consider reasons for not seeking or refusing treatment.

**Conclusion**

Up to 15,000 veterans in the VA remain untreated for HCV (VA, 2020). Veterans acknowledge the potential consequences of HCV and the means to treat it with oral medication (Clark & Gifford, 2015; Phillips & Barnes, 2016; Skolnik et al., 2019). However, exposure to stigma, trauma and substance use indicate that the decision to initiate treatment can be more complex (Garvey & Jones, 2019; Miller et al, 2012; van der Kolk, 2014). Veterans in this study recognized the risks of liver disease and possible death posed by HCV, forming a representation of consequences. They also understood that there were effective medications to treat HCV, forming a representation of controllability. However, for some, the HCV diagnosis unearthed feelings related to past stigma, trauma, and substance use, which had the potential to interfere with the decision to initiate treatment. Memories and emotions surrounding stigma, trauma and substance use may have constituted prototypes that were mismatched to representations of HCV controllability and consequences. However, these veterans overcame stigma, or reframed trauma and substance use in the light of ongoing recovery, forming new prototypes of HCV. These new prototypes matched the representations of controllability and consequences which had conferred the need for treatment. The CSM provided a flexible framework in this study to explore the
complex decisions that veterans make regarding treatment initiation, at a point in time when tolerable and effective treatment is available. The findings of this dissertation enriched the understanding of how veterans contending with stigma, trauma and substance use, initiated treatment for HCV, which has the potential to inform future research into this population.

Acknowledgements

I wish to thank the veterans who participated in this study and made my research possible. I also thank my dissertation committee chairperson, Dr. Rachel Jones of the School of Nursing at Northeastern University, and my committee members, Dr. Keith McInnes at the Edith Nourse Rogers Memorial Veterans Hospital (ENRM) and Dr. Ann Polcari at the School of Nursing for their invaluable assistance in the execution of this project. I also thank Dr. Allen Gifford of the Veterans Health Administration for serving as a co-investigator at ENRM. I thank the PhD Program at the School of Nursing at Northeastern University, for giving me the opportunity to pursue my doctorate, and the ENRM for the service and resources that made my dissertation possible.

This dissertation research was funded by the Gamma Scholar Award, granted by Gamma Epsilon, the Sigma Theta Tau chapter of Northeastern University. Doctoral training was funded by Northeastern University Student Graduate Assistantships provided by grants awarded by the Patient-Centered Outcomes Research Institute (PI: J. Griffith; NCT02405312) and the National Institute of Nursing Research (PI: R. Jones: R01NR014632). Additional funding for doctoral training was provided through the Jonas Scholars program, via the Jonas Center for Nursing and Veterans Healthcare. Financial support for terminal doctoral writing was provided by the Dissertation Completion Fellowship, provided by PhD Network at Northeastern University.
References


Garvey, C. M., & Jones, R. (in review). Is there a place for theoretical frameworks in the qualitative paradigm?


Hofmeister, M. G., Rosenthal, E. M., Barker, L. K., Rosenberg, E. S., Barranco, M. A., Hall, E.
AN EXPLORATION OF THE INFLUENCE OF STIGMA AND TRAUMA

https://doi.org/10.1002/hep.30297


https://doi.org/10.1177/1049732311431898


AN EXPLORATION OF THE INFLUENCE OF STIGMA AND TRAUMA

of Human Immunodeficiency Virus, Hepatitis C Virus, and Hepatitis B Virus Among homeless and nonhomeless United States Veterans. Clinical Infectious Diseases, 65, 252-258. https://doi.org/10.1093/cid/cix295


van der Kolk, B. A. (2014). The body keeps the score: Brain, mind and body in the healing of
## Appendix A: Institutional Review Board Approvals

<table>
<thead>
<tr>
<th>Department of Veterans Affairs</th>
<th>Memorandum</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Date:</strong> 9-13-16</td>
<td></td>
</tr>
<tr>
<td><strong>From:</strong> ACOS, Research &amp; Development</td>
<td></td>
</tr>
<tr>
<td><strong>Subj:</strong> Approval of New Project Submission</td>
<td></td>
</tr>
<tr>
<td><strong>To:</strong> D. Keith McInnes, ScD</td>
<td></td>
</tr>
<tr>
<td><strong>PROJECT TITLE:</strong> Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C: Pilot Study for Feasibility Among a Small Sample of United States Veterans</td>
<td></td>
</tr>
<tr>
<td><strong>PRINCIPAL INVESTIGATOR:</strong> D. Keith McInnes, ScD</td>
<td></td>
</tr>
<tr>
<td><strong>DATE OF R&amp;DC NOTIFICATION TO ACOS/R&amp;D:</strong> 9-13-16</td>
<td></td>
</tr>
<tr>
<td><strong>SUBCOMMITTEE APPROVALS COMPLETED:</strong></td>
<td></td>
</tr>
<tr>
<td>Scientific Review Subcommittee</td>
<td>6-15-16</td>
</tr>
<tr>
<td>Safety Review Subcommittee</td>
<td>7-19-16</td>
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<tr>
<td>Institutional Review Board</td>
<td>8-11-16</td>
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<tr>
<td>Animal Studies Subcommittee</td>
<td>N/A</td>
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<tr>
<td>ISO Review</td>
<td>8-26-16</td>
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<tr>
<td>PO Review</td>
<td>8-26-16</td>
</tr>
<tr>
<td><strong>COMMENTS:</strong> TRAINING VERIFIED AND CURRENT 9-13-16</td>
<td></td>
</tr>
</tbody>
</table>

The Research & Development Committee notified me in writing that the above new research project has been approved by all relevant committees, subcommittees, or other entities as noted. The principal investigator is hereby authorized to begin research activities on this project.

The IRB will coordinate periodic continuing reviews of this study, and IRB approval for this study will expire based on the terms of their initial approval.

---

P.B. Cipolloni, MD  
ACOS/Research & Development
AN EXPLORATION OF THE INFLUENCE OF STIGMA AND TRAUMA

Date: September 28, 2016
Principal Investigator(s): Rachel Jones
                      Casey Garvey
Department: School of Nursing
Address: 102 Robinson Hall
          Northeastern University
Title of Project: Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C: Pilot Study for Feasibility Among a Small Sample of United States Veterans
Approval Status: The above-mentioned protocol was reviewed and conditionally approved by the IRB at the Department of Veterans Affairs on 8/11/16. All work is being conducted through the VA and as such, the Northeastern IRB will rely on that review
Participating Sites: N/A
Informed Consents: One (1) signed consent form - VA only
Monitoring Interval: 12 months

APPROVAL EXPIRATION DATE: AUGUST 10, 2017

Investigator’s Responsibilities:

1. The informed consent form bearing the IRB approval stamp must be used when recruiting participants into the study.
2. The investigator must notify IRB immediately of unexpected adverse reactions, or new information that may alter our perception of the benefit-risk ratio.
3. Study procedures and files are subject to audit any time.
4. Any modifications of the protocol or the informed consent as the study progresses must be reviewed and approved by this committee prior to being instituted.
5. Continuing Review Approval for the proposal should be requested at least one month prior to the expiration date above.
6. This approval applies to the protection of human subjects only. It does not apply to any other university approvals that may be necessary.

C. Randall Colvin, Ph.D., Chair
Northeastern University Institutional Review Board

Northeastern University FWA #4630
### COMMITTEE FINDINGS:

All of the following criteria must be satisfied in order to approve research under 45 CFR 46.111 or 21 CFR 56.111:

1. The information given in the Informed Consent under the Description of Research by investigator is complete, accurate, and understandable to a research subject or a surrogate who possesses standard reading and comprehension skills.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

2. Legally effective informed consent will be obtained by the principal investigator or a trained and supervised designate under suitable circumstances that minimize the possibility of coercion or undue influence and give the prospective participant or representative sufficient opportunity to consider whether or not to participate.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

3. Informed consent will be appropriately documented.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

4. The risks to participants are minimized by using procedures which are consistent with sound research design and which do not unnecessarily expose participants to risk.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

5. The risks to participants are minimized whenever appropriate, by using procedures already being performed on the participants for diagnostic or treatment purposes.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

6. The risks to participants are reasonable in relation to anticipated benefits, if any, to participants, and the importance of the knowledge that may reasonably be expected to result.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

7. The selection of participants is equitable taking into account the purposes of the research, the setting in which the research will be conducted, the special problems of research involving vulnerable populations, the selection criteria, and the recruitment procedures.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

8. If subject is incompetent and surrogate consent is obtained, all following conditions have been met: a) the research can’t be done on competent subjects; b) there is no risk to the subject, or if risk exists the direct benefit to subject is substantially greater; c) if an incompetent subject resists, he will not have to participate; d) if there exists any question about the subject’s competency, the basis for decision on competency has been fully described.

   - [ ] YES
   - [ ] NO
   - [ ] N/A

9. When some or all of the participants are likely to be vulnerable to coercion or undue influence, such as children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons, are additional safeguards included in the study to protect the rights and welfare of these participants? (Note: Subpart B of the DHHS regulations specifies additional protections for pregnant women; Subpart C of the DHHS regulations, for prisoners; and Subpart D of the DHHS and FDA regulations, for children.)

   - [ ] YES
   - [ ] NO
   - [ ] N/A
Amendment: Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C: Pilot Study for Feasibility Among a Small Sample of United States Veterans

Principal Investigator: DK McInnes, ScD

10. If the subject is paid, the payment is reasonable and commensurate with the subject’s contribution?
   ✔ YES  ☐ NO  ☐ N/A

11. When appropriate, the research plan makes adequate provision for monitoring the data collected to ensure the safety of participants.
   ✔ YES  ☐ NO  ☐ N/A

12. When appropriate, there are adequate provisions to protect the privacy of participants.
   ✔ YES  ☐ NO  ☐ N/A

13. When appropriate, there are adequate provisions to maintain the confidentiality of data.
   ✔ YES  ☐ NO  ☐ N/A

14. If information has arisen that might affect the willingness of participants to continue to take part in the research, will it be provided to those participants?
   ✔ YES  ☐ NO  ☐ N/A

Comments: (Indicate if Expedited Review)

- ✔ Amendment: Expansion of the original pilot study to include: Updating title to "Illness Representation, Stigma Trauma, and Antiviral Treatment for Hepatitis C"; Added aim; Recruitment of additional 130 veterans; Limit sampling to veterans who have been treated for HCV within the past 6 months; Further defined "completion of HCV treatment" as "finished taking all medication"; Incorporate phone interviews as a method of data collection

- ☐ Expedited: (reason)

- ✔ HIPAA Waiver for recruitment  ☑ Informed Consent Waiver for recruitment
- ☐ No PHI collected
- ☐ Waiver of documentation of informed consent for telephone interviews

RECOMMENDATION:  ✔ APPROVE  ☐ DISAPPROVE/REVISE

SIGNATURE OF CHAIRPERSON/DESIGNEE:  [Signature]
John M. Wells, PhD

DATE:  4/12/18  EXPIRES:  7/31/18
AN EXPLORATION OF THE INFLUENCE OF STIGMA AND TRAUMA

Notification of IRB Action
Modification

Date: May 22, 2018
IRB #: 16-09-07

Principal Investigator(s): Rachel Jones
Casey Garvey

Department: Nursing
Bouvé College of Health Sciences

Address: 102 Robinson Hall
Northeastern University

Title of Project: Illness Representation, Stigma, Trauma and Antiviral Treatment for Hepatitis C

Modification: a) project now expanded into a full study; title has been changed.

Participating Sites: Department of Veterans Affairs – IRB modification approval received

DHHS Review Category: Expedited #7

Original Protocol Approval: September 28, 2016

Most Recent Approval: August 10, 2017 – renewed approval

Informed Consents: One (1) signed consent form – Consent obtained and maintained by the VA

Monitoring Interval: 12 months

APPROVAL EXPIRATION DATE: AUGUST 9, 2018

Investigator’s Responsibilities:
1. The informed consent form bearing the IRB approval stamp must be used when recruiting participants into the study.
2. The investigator must notify IRB immediately of unexpected adverse reactions, or new information that may alter our perception of the benefit-risk ratio.
3. Study procedures and files are subject to audit any time.
4. Any modifications of the protocol or the informed consent as the study progresses must be reviewed and approved by this committee prior to being instituted.
5. Continuing Review Approval for the proposal should be requested at least one month prior to the expiration date above.
6. This approval applies to the protection of human subjects only. It does not apply to any other university approvals that may be necessary.

C. Randall Colvin, Ph.D., Chair
Northeastern University Institutional Review Board

Nan C. Regina
Director, Human Subject Research Protection

Northeastern University FWA #: 4630
COMMITTEE FINDINGS:
All of the following criteria must be satisfied in order to approve research under 45 CFR 46.111 or 21 CFR 56.111:

1. The information given in the Informed Consent under the Description of Research by Investigator is complete, accurate, and understandable to a research subject or a surrogate who possesses standard reading and comprehension skills.

2. Legally effective informed consent will be obtained by the principal investigator or a trained and supervised designate under suitable circumstances that minimize the possibility of coercion or undue influence and give the prospective participant or representative sufficient opportunity to consider whether or not to participate.

3. Informed consent will be appropriately documented.

4. The risks to participants are minimized by using procedures which are consistent with sound research design and which do not unnecessarily expose participants to risk.

5. The risks to participants are minimized whenever appropriate, by using procedures already being performed on the participants for diagnostic or treatment purposes.

6. The risks to participants are reasonable in relation to anticipated benefits, if any, to participants, and the importance of the knowledge that may reasonably be expected to result.

7. The selection of participants is equitable taking into account the purposes of the research, the setting in which the research will be conducted, the special problems of research involving vulnerable populations, the selection criteria, and the recruitment procedures.

8. If subject is incompetent and surrogate consent is obtained, all following conditions have been met: a) the research can't be done on competent subjects; b) there is no risk to the subject, or if risk exists the direct benefit to subject is substantially greater; c) if an incompetent subject resists, he will not have to participate; d) if there exists any question about the subject's competency, the basis for decision on competency has been fully described.

9. When some or all of the participants are likely to be vulnerable to coercion or undue influence, such as children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons, are additional safeguards included in the study to protect the rights and welfare of these participants? (Note: Subpart B of the DHHS regulations specifies additional protections for pregnant women; Subpart C of the DHHS regulations, for prisoners; and Subpart D of the DHHS and FDA regulations, for children.)
### Report of Subcommittee on Human Studies

**Project/Program Title:** Amendment: Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C  
**Principal Investigator:** DK McInnes, ScD  
**VAMC:** Bedford  
**Initial Review Date:** November 8, 2018

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<tbody>
<tr>
<td>10. If the subject is paid, the payment is reasonable and commensurate with the subject's contribution?</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>11. When appropriate, the research plan makes adequate provision for monitoring the data collected to ensure the safety of participants.</td>
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<td></td>
<td></td>
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<tr>
<td>12. When appropriate, there are adequate provisions to protect the privacy of participants.</td>
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<td></td>
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<tr>
<td>13. When appropriate, there are adequate provisions to maintain the confidentiality of data.</td>
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<td></td>
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<tr>
<td>14. If information has arisen that might affect the willingness of participants to continue to take part in the research, will it be provided to those participants?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Comments:** (Indicate if Expedited Review)  
- [x] Amendment: Transition from quantitative approaches using valid and reliable instruments to qualitative approaches using in-depth interviews; altering data collection and analysis methods to conduct qualitative interviews.  
- [ ] Expedited: (reason)  
- [x] HIPAA Waiver for recruitment  
- [x] Informed Consent Waiver for recruitment  
- [ ] No PHI collected  
- [x] Waiver of documentation of informed consent

**Recommendation:** [x] APPROVE  
**Signature of Chairperson/Designee:** Donald R. Miller, ScD  
**Date:** 12/13/18  
**Expires:** 7/31/19

**Amendment:** qualitative interviews  
**Initial Review Date:** 11/8/18  
**Expiration Date:** 7/31/19
Date: January 14, 2019  
IRB #: 16-09-07
Principal Investigator(s): Rachel Jones  
Casey Garvey
Department: Nursing  
Bouvé College of Health Sciences
Address: 102 Robinson Hall  
Northeastern University
Title of Project: Illness Representation, Stigma, Trauma and Antiviral Treatment for Hepatitis C
Modification: a) study is being modified to now include qualitative approaches using valid and reliable instruments and in-depth interviews.
Participating Sites: Department of Veterans Affairs – IRB modification approval received
DHHS Review Category: Expedited #7
Original Protocol Approval: September 28, 2016
Most Recent Approval: September 28, 2018 – renewed approval
Informed Consents: One (1) signed consent form – Consent obtained and maintained by the VA
Monitoring Interval: 12 months

APPROVAL EXPIRATION DATE: JULY 25, 2019

Investigator’s Responsibilities:
1. The informed consent form bearing the IRB approval stamp must be used when recruiting participants into the study.
2. The investigator must notify IRB immediately of unexpected adverse reactions, or new information that may alter our perception of the benefit-risk ratio.
3. Study procedures and files are subject to audit any time.
4. Any modifications of the protocol or the informed consent as the study progresses must be reviewed and approved by this committee prior to being instituted.
5. Continuing Review Approval for the proposal should be requested at least one month prior to the expiration date above.
6. This approval applies to the protection of human subjects only. It does not apply to any other university approvals that may be necessary.

C. Randall Colvin, Ph.D., Chair  
Northeastern University Institutional Review Board

Nan C. Regina  
Director, Human Subject Research Protection

Northeastern University FWA #: 4630
Appendix B: Data Use Agreement

DATA USE AGREEMENT FOR THE RELEASE OF DE-IDENTIFIED DATA TO A NON-FEDERAL ENTITY

AGREEMENT FOR DE-IDENTIFIED DATA TRANSFER FROM VETERANS HEALTH ADMINISTRATION (VHA), Edith Nourse Rogers Memorial Veterans Hospital to Northeastern University

1. This Data Use Agreement (Agreement) is by and between Northeastern University, Boston, MA (hereafter the “Data Requestor”) entered into as of March 1, 2019 by and the Edith Nourse Rogers Memorial Veterans Hospital (hereafter the “Covered Entity”), a component of the U.S. Department of Veterans Affairs.

WHEREAS, the Covered Entity and the Data Requestor are committed to comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and its implementing regulations of Title 45 Code of Federal Regulations (C.F.R.) Parts 160 and 164 (“HIPAA Privacy and Security Rules”); and

WHEREAS, the purpose of this Agreement is to ensure the integrity and confidentiality of information disclosed by the Covered Entity to the Data Requestor under this Agreement in the form of De-identified Data (“Data”), as defined by the HIPAA Privacy Rule at 45 CFR § 164.514(a) and (b), for the purpose of “statistical analysis”; and

WHEREAS, the parties acknowledge and recognize that the De-identified Data (“Data”) will not be disclosed to the Data Requestor until the parties execute this Agreement.

TERMS OF THE AGREEMENT:

1. All provisions of this Agreement that apply to the Data Requestor also apply to any employee, contractor, subcontractor, or other agent of the Data Requestor. The Data Requestor will ensure that its employees, contractors, subcontractors, and other agents abide by the terms and conditions of this Agreement. Upon written request from the Covered Entity, the Data Requestor shall provide verification of compliance within three (3) business days.

2. The Data Requestor will use the Data provided by the Covered Entity under this Agreement to support evidence-based medical research and statistical analysis that informs health care policy and improves patient care. The specific VHA data elements being provided to the Data Requestor to support these analyses are listed in Attachment A. Fees associated with providing the Data as outlined in 38 CFR § 1.526(i) may be imposed. The parties further agree that the Covered Entity makes no representation or warranty, either implied or express, with respect to the accuracy of the Data.

3. For the purpose described in paragraph 2 only, the Covered Entity will provide the Data Requestor with Data. The Covered Entity and the Data Requestor acknowledge and affirm that the Data is de-identified under the Expert Determination provisions of the HIPAA Privacy Rule and is therefore not subject to its requirements in its current state. The Covered Entity and Data
Requestor agree to abide by limitation, qualifications, conditions, and/or restrictions set forth in the HIPAA Expert Determination associated with this de-identified Data. The Covered Entity and the Data Requestor acknowledge and affirm that the Data is also non-identifiable under the Privacy Act, 5 U.S.C. § 552a, and 38 U.S.C. §§ 5701 and 7332, and is therefore not subject to those statutes in its current state.

4. The following named individuals are designated as their agencies' Points of Contact (POC) for performance of the terms of the Agreement. All questions of interpretation or compliance with the terms of this Agreement should be referred to the VHA official named below. The Data Requestor agrees to notify the Covered Entity within fifteen (15) calendar days of any change in the named contact.

VHA's Point-of-Contact on behalf of VHA Bedford Medical Center
Name: Keith McInnes
Title: Research Scientist/Principal Investigator
Telephone: 781-687-3507

Other Points-of-Contact on behalf of VHA Bedford Medical Center
Name: Casey Garvey
Title: WOC Student Researcher/Co-Investigator
Telephone: 978-930-5212

Points-of-Contact on behalf of Northeastern University, Boston MA
Name: Rachel Jones
Title: Associate Professor
Telephone: 617-373-6806

5. The Covered Entity will retain ownership of the original data and the Data Requestor will receive a copy. The copy of the Data transferred under this Agreement becomes the property of the Data Requestor subject to the terms of this Agreement. The Data provided may not be used or accessed by the Data Requestor for any purpose other than as outlined in Paragraph 2 of this Agreement. The Data Requestor shall not disclose, release, reveal, show, sell, rent, lease, loan, or otherwise grant access to the Data covered by this Agreement to any person or entity outside of the Data Requestor except as otherwise required by law.

6. The Data Requestor agrees that it will not identify, contact, or attempt to identify or contact the individuals whose information is contained in the Data. The Data Requestor also agrees that it will not link or attempt to link the Data with other data sources for such purposes. Any attempt by the Data Requestor to re-identify individuals who information is contained in the Data will constitute a material breach of the terms of this Agreement, and this Agreement will be considered terminated as outlined in Paragraph 12.

U-193574 Garvey VA DUA
7. VHA will ensure the secure transfer of the data to Northeastern University, Boston, MA. The method of transfer will be either through the Safe Access File Exchange (SAFE) system or through the physical transfer of data on either a CD or DVD. If the transfer of data is accomplished through the physical transfer of data on a CD or DVD, the disks will be prepared by an authorized research staff and then mailed directly to Northeastern University.

8. Northeastern University, Boston, MA its contractors and agents, shall establish appropriate administrative, technical, procedural, and physical safeguards in accordance with industry practice, to protect the confidentiality and to prevent unauthorized access to, use, or disclosure of the Data provided by the Covered Entity.

9. If a Data Requestor’s employee, contractor, or agent becomes aware of the theft, loss or compromise of any device used to transport, access or store the Data, such employee, agent, or contractor must immediately report the incident to his or her supervisor. Should any security incident or event involve VHA Data (i.e. the theft, loss, compromise, or destruction of any device used to transport, access, or store VHA Data) covered by this Agreement, or the incident places VHA Data at risk of loss, unauthorized access, misuse or compromise, the Data Requestor will notify the VHA Point-of-Contact by phone or in writing within 24 hours of detection. The Data Requestor will provide details of the security event, the potential risk to VHA Data, and the actions that have been or are being taken to remediate the issue.

10. Access to the Data shall be restricted to authorized employees, contractors, subcontractor, and agents of the Data Requestor requiring access to perform their official duties as authorized by this Agreement. The Data Requestor shall inform such personnel of: (1) the confidential nature of the information; (2) safeguards required to protect the information; (3) the administrative, civil, and criminal penalties for noncompliance contained in applicable Federal laws; and (4) that their actions can lead to the immediate termination of this Agreement by the Covered Entity. The Data Requestor agrees to limit access to, disclosure of, and use of Data provided under this Agreement to the minimum number of individuals needing access to the Covered Entity's data to perform their duties as authorized by this Agreement.

11. The Data Requestor and his heirs, executors, administrators or assigns (including any and all entities with which he is affiliated, including but not limited to Northeastern University, Boston, MA and any successor entity) further agree to reimburse, indemnify and hold harmless the VA, its agents, servants, contractors and employees from and against any and all such causes of action or claims brought by any claimant or plaintiff who alleges that, as a result of the information released by the VA to Data Requestor in response to the modified Freedom of Information Act Request and this Agreement, that claimant or plaintiff's identity and medical information was released by the VA.
12. This Agreement may be terminated by the Covered Entity in the event of a material breach of the Agreement upon written notice. This Agreement may be terminated by the Data Requestor at any time for any reason upon 30-days' written notice. Once this Agreement is terminated, the Data Requestor has no authority to use, access, release, or disclose the Data. Within 15 days of the receipt of the Notice of Termination of the Agreement, the Data Requestor must, at its own expense, destroy the Data and provide a Certificate of Destruction signed by Northeastern University, Boston, MA to the VHA POC listed in Paragraph 4 (or his or her successor).

13. All questions of interpretation or compliance with the terms of this Agreement shall be referred to the VHA POC named in Paragraph 4 (or his or her successor). In the event that any issues arise regarding performance of this Agreement, the parties shall, through counsel, make reasonable efforts to resolve those issues outside of court. If such reasonable efforts do not resolve the dispute, either party may commence action to enforce this agreement in federal court.

14. This Agreement supersedes any and all previous agreements related to this project or data exchange. The terms of this Agreement can be changed only by a written modification to the agreement by the agency signatories (or their designated representatives) to this Agreement or by the parties adopting a new agreement in place of this Agreement.

15. This Agreement is effective on the date of signature of the last signatory to the Agreement. Facsimiles of signatures shall constitute acceptable, binding signatures for purposes of this Agreement.
Appendix C: Consent Form

Department of Veterans Affairs

<table>
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<tr>
<th>VA RESEARCH CONSENT FORM</th>
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Participants Name: ___________________________ Date: ________________

Social Security Number: _______________________

Principal Investigator: Keith McInnes

VAMC: Bedford, MA

Title of Study: Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C

Sponsor of the Study: Sigma Theta Tau International [Nursing Honor Society], and VA Medical Center, Bedford, Massachusetts

1. Purpose of study and how long it will last:

You are invited to participate in a research study about hepatitis C. The study is to understand how people decide to get treated for hepatitis C. In this study we hope to learn whether people’s decision to be treated for hepatitis C is affected by stigma and symptoms of trauma. You have been invited because you have hepatitis C and are a veteran. Your participation will last for approximately one and a half hours.

2. Description of the study including procedures to be used:

This study will collect information from veterans about what they think about their Hepatitis C, and how they made the choice to undergo oral antiviral treatment. To collect this information, study researchers will interview veterans face to face to discuss thoughts and feelings about their Hepatitis C, their experiences with stigma and trauma, and why they chose to undergo treatment. An interview guide will be used. Veterans will also complete a short questionnaire to collect data about veterans’ age, race, income, service history, medical history, Hepatitis C status, and substance use history. These interviews will be audio-recorded, and physical notes will be taken by the researcher during the interview. This study will seek to recruit up to 30 individuals.

If you wish to participate in the study, you will be interviewed by a researcher in a private room in-person at the VA in Bedford. The researcher will first ask you some background questions using a questionnaire to get information about, including your age, race, medical history and any substance use history. Next, the researcher will explain again the purpose of the study and what the interview will entail. The researcher will obtain permission from you to audio-record the interview and take notes. These recordings will be used to make sure we remember what you said. The researcher will also ask that you select an alternate name to use for yourself during the course of the interview so as to protect your identity. When the interview itself begins, the researcher will turn on the audio-recording device, introduce themselves for the record, confirm that you have given permission to record the interview, and thank you for your participation. The interview will start with open-ended questions related to your views on Hepatitis C, your experiences with stigma and trauma, and how you made the choice to undergo treatment. You will be able to take the discussion wherever you wish, though the researcher may ask additional questions to gain more detail.

We know that some of the questions in the interview are about sensitive subjects. You may refuse to answer specific questions or choose to stop participating in the study at any time. What you do for this study is not related to your usual VA care. Being in the study will not affect any services you get at the VA, and choosing to stop participating in the study will also not affect any of your services at the VA. If at any time you feel upset during the course of the interview, please let the researcher know. That way he can contact your health care provider, walk you to the mental health clinic in Building 78 here at VAMC Bedford, or help you call the VA Crisis Line.

After the interview is complete, or you have decided to stop, the audio-recording device will be turned off, and the interviewer will ask if you have any additional questions, concerns or details you wish to provide; additional paper notes may be taken at this time. Once any and all concerns or questions have been answered the study will be over for you. The researcher will give you a $50.00 gift card as payment for your time. You will also be given the
**Participants Name:** __________________________

**Social Security Number:** ______________________

**Principal Investigator:** Keith McInnes

**Title of Study:** Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C

**Sponsor of the Study:** Sigma Theta Tau International [Nursing Honor Society], and VA Medical Center, Bedford, Massachusetts

researcher’s contact information if you need to get a hold of him to ask questions or to comment on things that you hadn’t thought of before.

As the study continues and we analyze the data, we may need to re-contact you to get additional details on things that we discussed during today’s interview. We will ask your permission to re-contact you later by phone to ask additional questions to clarify topics that come up in today’s interview.

3. **Description of any procedures that may result in discomfort or inconvenience:**

It is possible that you will feel upset while completing the interview because the topics in the interview are sensitive and may bring up sad feelings. Also, we recognize that completing the interview may take time—up to an hour and a half—and that you may become tired or bored. We want to remind you that you can, at any time, choose to stop participating in the study if you become uncomfortable, tired, or upset. You can take breaks at any time if you need to.

4. **Expected risks of study:**

This study is about sensitive issues. It is possible that you may become upset while answering questions about stigma or trauma that you might have experienced in the past. Also, you might get bored from answering questions for up to an hour and a half.

A private room at or near the Bedford VA medical center hepatitis clinic will be provided for you to complete the interview.

If you feel upset during the study, you can talk to the researcher about whether it would be a good idea to stop the interview and stop being in the study. You can also talk to the researcher about whether to speak with a VA mental health specialist. If you wish to speak with a mental health specialist, the researcher will offer to contact your provider, and/or walk you to the mental health clinic. We will also be able to help you contact the Mental Health Veterans Crisis Hotline at (800) 273-8255.

**Confidentiality of Information:**

Participation in research may involve a loss of privacy. For example, it is possible that data from the study could be lost, or someone outside the study could see your information. To avoid this, your research records will be kept as confidential as possible. Audio-recordings of interviews will be stored on the VA network behind a firewall, which can only be accessed by a key card and unique pin number. These recordings will not be shared outside the VA. Once audio-recordings have been transferred to the VA network, any copies on the audio-recording device will be deleted. Transcriptions of those audio-recordings and notes taken during the interview will also be stored on the VA network. Data transcribed from the questionnaires collected prior to the interview will also be stored on the VA network. Your information will not be linked back to you. Only a code number will identify your research information. The code number will not be based on any information that could be used to identify you, such as your name, address, phone number, medical record number, or social security number. The master list linking names to
There are no direct benefits of studying the effects of stigma and trauma. The most important direct benefit is being able to participate in the study and receive the services that will be provided to you as part of the study.

5. Expected direct benefits of study:

There are no direct benefits from participating in this study. However, the information you provide in this study may help improve our understanding of how US veterans decide whether to have treatment for hepatitis C. Such information may help improve care for veterans with hepatitis C.

6. Alternative treatment available:

The alternative to this study is to not participate in this study.

7. Use of research results/Confidentiality:

Multiple investigators will be required to review and analyze transcripts and notes from your interview in order to produce findings. Copies of transcripts of interviews and notes taken during and after interviews may be shared with a study investigator located at the Northeastern University School of Nursing. Northeastern University will only ever receive interview transcripts and notes after all of your directly identifying information in them, such as your name, address, or specific dates, have been removed. Copies of interview transcripts and notes may be sent to Northeastern University electronically using secure email, or through delivery of physical copies. Any information that is received by Northeastern University will be stored securely. Electronic copies of interview transcripts and notes will be kept on an encrypted database on a single computer, and any physical copies will be kept in a locked cabinet. Any copies of interview transcripts or notes received by Northeastern University will be destroyed once they are no longer needed for analysis. None of the information that you provide in your interview or any notes that
AN EXPLORATION OF THE INFLUENCE OF STIGMA AND TRAUMA

Participants Name: ___________________________ Date: ________________

Social Security Number: ___________________________ VAMC: Bedford, MA

Principal Investigator: Keith McInnes

Title of Study: Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C

Sponsor of the Study: Sigma Theta Tau International [Nursing Honor Society], and VA Medical Center, Bedford, Massachusetts

are taken before or after your interview will be shared between the Bedford VA or Northeastern University without a written agreement on the use and safeguarding of your information signed by both the Bedford VA and Northeastern University, and approval by the Institutional Review Board at Northeastern University.

If results of this study are reported in medical journals or at meetings, you will not be identified by name, by recognizable photograph, or by any other means without your specific consent. Your medical records will be maintained according to VA requirements.

8. Special Circumstances:

You will be given a $50.00 gift card to compensate you for your time being in this research study. A researcher will give you the gift card right after you finish the interview.

9. Additional Elements of Informed Consent

1. It is possible that this study may involve currently unforeseeable risks to you as a participant.
2. In cases where you become very upset during the course of the study, and it is in your best interest to stop participating and seek mental health assistance, you may be removed from the study without your consent.
3. You will be responsible for any costs of transportation to the VA for study purposes.
4. Any significant new findings developed during the course of the research that may affect your willingness to participate in this study will be provided to you.
5. This study seeks to recruit up to 30 participants.
6. Future Use of Data. We would like to use the information you provide in this study for future research. You will be offered the option of allowing us to use your information in other research studies when you sign this consent form.
7. Re-contact: You may be re-contacted by phone after you finish the interview today in order to get additional information or clarification. You may also be re-contacted if we determine that the data you provide or other information was lost or seen by people who should not have seen it.
8. Payment for Participating in the Study: Right after you finish the interview you will be given a $50.00
gift card to compensate you for your time in this study.
9. Disclosure of Results. At your request, we will give you a summary of the results of this study.

Future Use of Data

The data will also be stored in the Veterans HCV Representations Data Repository, a new data repository being set up here at the ENRM VA Hospital for future research studies pertaining to on stigma, trauma and illness representations among veterans with HCV. All data will be stored and maintained according to VA regulations and only investigators approved through the Veterans HCV Representations data repository committee will have access to this data. Any future use of the data will be reviewed and approved by this committee. The creation and management of this data repository will be approved by the hospital Research and Development Committee before any of the data from this study will be stored in it for future use.
Participants Name: _____________________________ Date: ______________

Social Security Number: _____________________________ VAMC: Bedford, MA

Principal Investigator: Keith McInnes

Title of Study: Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C

Sponsor of the Study: Sigma Theta Tau International [Nursing Honor Society], and VA Medical Center, Bedford, Massachusetts

We would like to use your interview and questionnaire answers from this study in future research. Do you give your permission for us to use the information provided in your interviews in future research?

☐ Yes  ☐ No

Re-Contacting for Additional Details or Follow-up Interview

As we analyze data in the study, the investigators might require additional information from participants that they have interviewed in the past. Investigators may need to re-contact participants to ask questions on unclear topics, gain additional details on specific topics, and confirm that findings make sense to both the participants and the researchers. This is done so that the findings of this study reflect the data collected during the interviews as much as possible.

We would like to be able to re-contact you to schedule a one-time phone discussion to ask questions and get additional details if needed after your in-person interview. Do you give your permission for us to re-contact you after your interview to ask further questions?

☐ Yes  ☐ No

RESEARCH PARTICIPANTS’ RIGHTS: I have read, or have had read to me all of the above. A study staff member has explained the study to me and answered all of my questions. I have been told of the risks or discomfort and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of rights to which I am entitled. I may withdraw from this study at any time without penalty or loss of VA or other benefits to which I am entitled.

The results of this study may be published, but my records will not be revealed unless required by law.

A veteran-participant does not have to pay for care received as a participant in a VA research project except in accordance with federal law. Certain veterans have to pay co-payments for medical care and services provided by VA. In case there are medical problems or questions, I have been told I can call the direct hospital line at 781-687-2000 during the day or after hours and page the doctor on call. For questions related to the study, I have been told I can call Casey Garvey during the day or after hours at 978-930-5212. VA Medical Facilities shall provide, or arrange for, necessary medical treatment to a research subject injured as a result of participation in a research project. This does not apply to treatment for injuries due to non-compliance by the subject with the study procedures. If I have any questions, concerns, or complaints regarding my rights as a research subject I may call Joseph Squicciarini at 781-687-2926. No money has been set aside for compensation in case of injury as a result of participating in this study however I understand that I would still have the right to file any legal action.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand
<table>
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<tr>
<th>Department of Veterans Affairs</th>
<th>VA RESEARCH CONSENT FORM</th>
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<tr>
<td>Participants Name:</td>
<td>Date:</td>
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<tr>
<td>Sponsor of the Study: Sigma Theta Tau International [Nursing Honor Society], and VA Medical Center, Bedford, Massachusetts</td>
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</table>

what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

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<thead>
<tr>
<th>Participant's Signature</th>
<th>Date</th>
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<tbody>
<tr>
<td>Signature of Participant's Representative*</td>
<td>Participant's Representative (print)</td>
</tr>
<tr>
<td>*Only required if subject not competent.</td>
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</tr>
<tr>
<td>Signature of Investigator</td>
<td>Signature of the person obtaining consent</td>
</tr>
</tbody>
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Appendix D: Recruitment Material

Participant ID: ____________________
Investigator: ____________________
Date: __________

Hello, I’m looking for Mr./Ms./Mrs. PARTICIPANT LAST NAME.

Hello Mr./Ms./Mrs. PARTICIPANT LAST NAME, my name is INVESTIGATOR NAME, calling from the Center for Healthcare Organization and Implementation Research at the VA in Bedford.

I’m calling because you were identified in VA medical records as someone eligible to participate in our research study on illness perceptions, stigma and trauma in US veterans who have taken oral medication for treatment of Hepatitis C. Are you interested in learning more?

A few weeks back, we mailed out letters from your clinician here and from the investigation team detailing our project, which mentioned we’d be calling. We wanted to wait a few weeks to give you time to think about whether or not you wanted to participate, and we’re calling now to see if you would be interested.

Would you be interested in participating in our research study?
- Yes  ____ (Proceed to 1.)
- No   ____ (Proceed to 2.)
- Unsure  ____ (Proceed to 3.)

1. IF YES

I’m glad to hear that you’re interested in participating. I’d just like to ask a few questions before we go further.

a. Can you confirm that you have received oral antiviral medication for your Hepatitis C at the VA? (If YES, continue to b., if NO, proceed to NOT ELIGIBLE)
- Yes  ____
- No   ____

b. Did your most recent treatment for your Hepatitis C include an injection (such as Interferon)? (If NO, continue to c., if YES, proceed to NOT ELIGIBLE)
- Yes  ____
- No   ____

c. Are you getting any Hepatitis C medication outside the VA? (If NO, continue to DETAILS OF RESEARCH STUDY, if YES, proceed to NOT ELIGIBLE)
- Yes  ____
- No   ____

<<<DETAILS OF RESEARCH STUDY>>>

Thank you for answering those questions. Before we schedule an interview I just want to give you a few additional details about the study. This study will involve interviews between you and a researcher at the VA in Bedford, where you’ll have the opportunity to talk about your perceptions of Hepatitis C and any experiences you might have had with stigma or trauma. These interviews will be audio-recorded and notes will be kept by the researcher. We’ll have a private room set up with refreshments for us to conduct the interview. The interview itself may take up to an hour and a half, and at the conclusion you’ll receive a $50.00 gift card as compensation. There’s no direct benefit to you for participating in the study, but your participation in this study will help the VA understand how illness perceptions, stigma and trauma affect hepatitis C treatment in US veterans, which may inform future practice. We want you to know that the study involves discussing sensitive topics and you may become upset or
fatigued during the interview. Your participation is entirely voluntary, and will be able to skip questions or stop the interview at any time.

Are you still interested in participating? (If YES, continue to SCHEDULING, if NO, proceed to 2.)
  - Yes ____
  - No   ____

<<<SCHEDULING>>>

The next step is to set up a time for you to enroll in the study and complete an interview with a researcher.

Do you have a day and time that would work for you?

SCHEDULED DATE/TIME: ____________________

We have private rooms set up at Building 70 at the VA in Bedford. Do you know how to get to Building 70? (PROVIDE DIRECTIONS IF NO; DISCUSS ALTERNATE SITES AT ENRM IF PREFERRED).

Do you have any other questions or concerns?

Great. Thank you again for your consideration in participating in this research study. We look forward to meeting with you. If you have any questions or concerns, please don’t hesitate to call us at (XXX) XXX-XXXX.

Thank you, and take care.

(HANG UP)

<<<NOT ELIGIBLE>>>

Thank you for answering those questions. We’re specifically looking for veterans who receive care at the VA and who are not getting hepatitis C medication outside the VA for our research/veterans who have taken the oral-only treatment for HCV. So at this time, you are not eligible for participation in this research study. We apologize for any confusion or inconvenience.

Do you have any questions or concerns about this project?

Again, we thank you for your interest in participating in this study, and we regret that we will not be able to work with you on this project. If you have any other questions or concerns about this project or our interaction today, please don’t hesitate to call us at (XXX) XXX-XXXX.

Thank you, and take care.

(HANG UP)

2. IF NO

Okay. We thank you for your consideration.

Do you have any questions or concerns about this project that you’d like us to address?

If you have any other questions or concerns about this project or our interaction today, please don’t hesitate to call us at (XXX) XXX-XXXX.
Thank you, and take care.

(HANG UP)

3. IF UNSURE

We understand. Do you have any questions or concerns that we can address that might help you make a decision?

IF VETERAN NO LONGER HAS LETTER: Would you like us to send you another letter explaining our project?

AFTER ANSWERING QUESTIONS (AS APPLICABLE): Are you still unsure about participating or have you come to a decision?

IF DECIDED TO PARTICIPATE: Proceed to 1.

IF DECIDED NOT TO PARTICIPATE: Proceed to 2.

IF STILL UNSURE: Continue immediately below

<<FAREWELL FOR NOW>>>

We understand. Is there a time that you would like us to call you back?
- Day/Time to call back: ____________________

We understand. If you have any other questions or concerns about this project or our interaction today, or if you would like to participate in the study, please don’t hesitate to call us at (XXX) XXX-XXXX.

Thank you, and take care.

(HANG UP)
Dear Veteran,

You are invited to take part in a research study about how veterans with hepatitis C make the choice to get treated.

You were identified in VA medical records as a veteran who has or once had hepatitis C.

What is this research study about?
- This research study seeks to understand how veterans with Hepatitis C made the choice to take oral medication to treat the illness. This study also seeks to explore the illness perceptions veterans with Hepatitis C, and experiences of stigma and trauma.

Do I need to have PTSD to participate in this research study?
- We're interested in how trauma symptoms might affect decisions to undergo treatment, but you don't need to have ever been diagnosed with PTSD to participate in this study.

If I want to be in this research study, what am I being asked to do?
- You will be asked to complete an interview with a researcher. The researcher will ask you general questions about your Hepatitis C, how you decided to get treated, and any experiences with stigma or trauma that you might have had. You will also be asked to complete a one-time questionnaire to collect information about your age, race, medical history, any history of substance use and other information.
- Participation in this study is entirely voluntary, and will not affect the services and benefits you receive from the VA. We are interested in your honest opinions: there are no right or wrong answers to questions asked during the interview, and your responses will be kept confidential.
- The interview will take about an hour and a half, and once done, you will be given a $50.00 gift card.

What are the benefits of participating?
- There are no direct benefits to you for participating, but your participation in this research study will help the VA understand how illness perceptions, stigma and trauma affect hepatitis C treatment in US veterans, which may inform future practice.

Who is eligible to participate?
- U.S. veterans over the age of 18 who have or have had Hepatitis C, who have begun taking oral antiviral medication for Hepatitis C at the VA within the past 6 months and not receiving HCV medication outside the VA.

How do I learn more about the research study or enroll?
- The study team will call you by phone in about two weeks to see if you’d be interested in learning more about the study or joining. You may also call the study team directly using the phone numbers below if you are interested in learning more or joining now.

I don't want to be a part of the study: can I let you know not to call me?
- If you don’t want to be in the study, please call at (PHONE NUMBER PENDING) and ask to be taken off the call list.

Who can I call if I have other questions about the study?
- Study Co-Investigator: PENDING (PENDING PHONE NUMBER)

Who can I call to confirm this is a VA-approved study?
- Joseph Squicciarini: 781-687-2926

Thank you and take care.

Sincerely,

INVESTIGATOR NAME AND CREDENTIALS HERE
Dear Veteran,

Thank you for your past participation in the Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C Study.

The research team is conducting a new phase of this project, and will be conducting in-depth interviews with veterans. These interviews will be exploring how veterans made the choice to undergo treatment for Hepatitis C, as well as their perceptions of the illness, and experiences with stigma and trauma. We would like to extend an invitation to you to return and conduct an additional interview with the research team.

**What is this research study about?**
- This research study seeks to understand how veterans with Hepatitis C made the choice to take oral medication to treat the illness. This study also seeks to explore the illness perceptions veterans with Hepatitis C, and experiences of stigma and trauma.

**Do I need to have PTSD to participate in this research study?**
- We’re interested in how trauma symptoms might affect decisions to undergo treatment, but you don’t need to have ever been diagnosed with PTSD to participate in this study.

**If I want to be in this research study, what am I being asked to do?**
- You will be asked to complete an interview with a researcher. The researcher will ask you general questions about your Hepatitis C, how you decided to get treated, and any experiences with stigma or trauma that you might have had. You will also be asked to complete a one-time questionnaire to collect information about your age, race, medical history, any history of substance use and other information.
- Participation in this study is entirely voluntary, and will not affect the services and benefits you receive from the VA. We are interested in your honest opinions: there are no right or wrong answers to questions asked during the interview, and your responses will be kept confidential.
- The interview will take about an hour and a half, and once done, you will be given a $50.00 gift card.

**What are the benefits of participating?**
- There are no direct benefits to you for participating, but your participation in this research study will help the VA understand how illness perceptions, stigma and trauma affect hepatitis C treatment in US veterans, which may inform future practice.

**Who is eligible to participate?**
- U.S. veterans over the age of 18 who have or have had Hepatitis C, who taken oral antiviral medication for Hepatitis C at the VA and not receiving HCV medication outside the VA.

**How do I learn more about the research study or enroll?**
- If you wish to learn more about the study or enroll, you may call Study Co-Investigator Casey Garvey at 978-870-9560 and schedule an interview. We will not call you first, so if you are not interested in learning more or participating in this study, you may discard this letter.

**Who can I call if I have other questions about the study?**
- Study Co-Investigator: PENDING (PENDING PHONE NUMBER)

**Who can I call to confirm this is a VA-approved study?**
- Joseph Squicciarini: 781-687-2926

Thank you and take care.

Sincerely,

INVESTIGATOR NAME AND CREDENTIALS HERE
Dear Veteran,

I hope this letter finds you doing well.

As a part of the services that the VA provides to veterans, we also do a lot of research to improve the care of Veterans. I wanted to let you know about a study that you might be interested in participating in. A VA research team is interested in speaking with Veterans with hepatitis C. Participation is not required for you to continue getting care at the VA. If you think that you might be interested in participating in this study, please read the letter the research team has attached below.

Thank you and take care!

Sincerely,

Allen L. Gifford, MD
Appendix E: Data Collection Material

Illness Representation, Stigma, Trauma, and Antiviral Treatment for Hepatitis C Interview Guide
Version Date 10-12-2018

The following questions are open-ended to allow participants to freely express their answers to the questions. Additional questions may be asked by interviewers to follow-up or to clarify participants’ responses. Questions may also be omitted as required. This guide is subject to change as the study progresses.

CONFIRMATION: Has the participant given permission to audio-record the interview:

___ Yes  ___ No

1. How did you learn that you had HCV?
   a. Prompt if relevant: What led you to get HCV tested?
2. What, if anything, did you know about HCV before you were diagnosed?
   a. Prompt if relevant: Was there anything that worried you about your HCV before you were treated?
3. What do you think caused you to become infected?
4. What sort of feelings come up when you think about what caused you to become infected?
   a. Prompt if relevant: How did you get through these feelings?
5. Can you walk me through how you made the choice to get treated?
6. How did you expect the treatment process to go?
   a. Follow-up if not addressed: How did it go?
7. Have you ever experienced or been exposed to something that you felt was traumatic?
   a. Prompt if relevant: How do you think this related to your HCV?
   b. Prompt if relevant: How do you think this related to your choice to get treated?
8. What was your everyday life like after you were diagnosed with HCV?
   a. Prompt if relevant: After the diagnosis, what, if anything, did you do differently?
   b. Prompt if relevant: How did people treat you if they knew you had HCV?
   c. Prompt if relevant: What was challenging about having HCV?
   d. Prompt if relevant: Was there anything that was helpful to you while you were living with HCV?
9. Can you describe how you thought clinicians might treat you with this diagnosis?
   a. Follow-up if not addressed: And how were you treated?
10. What symptoms of HCV, if any, did you experience?
11. Now that you’re undergoing treatment/you’ve finished treatment, how do you feel?
   a. Prompt if relevant: If you were to do it again, is there anything that you or others in the treatment process could have done differently?
   b. Prompt if relevant: What advice, if any, might you give to a veteran with HCV?
Data Collection Instructions

Thank you for your participation in this study.

Before we begin the interview, we’d like you to complete a brief questionnaire. It will ask you for background information, such as your service history, information about your Hepatitis C infection, and other health information. This questionnaire will also ask you about any experiences with substance use (including alcohol and drug use) that you might have had in your life.

After completing the questionnaire, we will begin the in-depth interview.
Demographics:

1. Age: _____

2. Sex: _____

3. Which race/ethnicity best describes you? (Circle all that apply)
   ① African American/Black
   ② Asian American
   ③ Caucasian/White
   ④ Hispanic/Latino
   ⑤ Pacific Islander
   ⑥ American Indian, Alaskan Native
   ⑦ Other________________________

4. What is the highest level of education that you have achieved to date?
   ① Elementary school (1st-6th grade)
   ② Middle school (7th-8th grade)
   ③ High school (9th-12th grade)
   ④ Some college/Vocational school
   ⑤ Associates degree
   ⑥ College degree (4 year degree)
   ⑦ Graduate Degree

5. What is your household income?
   ① $5,000 - $10,000/year
   ② $10,001 - $15,000/year
   ③ $15,001 - $25,000/year
   ④ $25,001 - $35,000/year
   ⑤ $35,001 - $45,000/year
   ⑥ More than $45,100/year

6. What is your marital status?
   ① Single, never married
   ② Married
   ③ Living with partner (not married)
   ④ Divorced/Separated
   ⑤ Widowed
Service History:

7. Branch(es) of Service:
   ① US Army
   ② US Navy
   ③ US Marine Corps
   ④ US Air Force
   ⑤ US Coast Guard

8. Year of Enlistment/Commission: __________

9. Year of Discharge/Retirement/Separation: __________

10. Job within Military: ______________________________

11. Did you experience combat while in the military?
   ① Yes
   ② No
   ③ I Don’t Know

Hepatitis C Information:

12. When were you diagnosed with Hepatitis C? __________
    I Don’t Know □

13. Have you received genotyping for your Hepatitis C infection?
   ① Yes
   ② No
   ③ I Don’t Know

14. Have you been diagnosed with cirrhosis?
   ① Yes
   ② No
   ③ I Don’t Know

14a. If yes, what stage cirrhosis are you?
   ① Stage 1
   ② Stage 2
   ③ Stage 3
   ④ Stage 4
   ⑤ I Don’t Know

15. Have you ever been diagnosed with hepatocellular carcinoma (a form of liver cancer?)
   ① Yes
   ② No
   ③ I Don’t Know
16. When did you last begin treatment for your Hepatitis C? ______________ 7

16a. Have you completed treatment (finished taking all medication) for your Hepatitis C?
   ① Yes (Skip to 16)
   ② No (Go to 18b)

16b. If no to 15a, are you currently undergoing treatment right now?
   ① Yes (Skip to 16)
   ② No (Go to 18c)

16c. If no to 15b, did you begin treatment, but had to stop before completing it?
   ① Yes
   ② No

17. Have you made multiple attempts at treatment for HCV in your lifetime?
   ① Yes
   ② No (skip to 18)

17a. If yes to 17, how many past attempts at treatment have you made? ___________

18. What oral HCV medication have you taken most recently?
   ① Ledipasvir/Sofosbuvir (Harvoni)
   ② Sofosbuvir (Sovaldi) + Ribavirin
   ③ Ledipasvir/Sofosbuvir (Harvoni) + Ribavirin
   ④ Elbasvir/Grazoprevir (Zepatier)
   ⑤ Sofosbuvir (Sovaldi) & Daclatasvir (Daklinza) + Ribavirin

   ⑥ Other (Please Specify______________________________)
   ⑦ I Don’t Know
19. Do you have any of the following medical conditions? (Check One on Each Line)

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<th>No</th>
</tr>
</thead>
<tbody>
<tr>
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<td>□</td>
</tr>
<tr>
<td>Arthritis</td>
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<td>□</td>
</tr>
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<td>Cancer</td>
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<td>□</td>
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<tr>
<td>Heart Disease</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>High Blood Pressure</td>
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<td>□</td>
</tr>
<tr>
<td>Kidney Trouble</td>
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<tr>
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<td>Migraine Headaches</td>
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<td>□</td>
</tr>
<tr>
<td>Repeated Bladder Disorders</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Repeated Trouble with Neck, Back or Spine</td>
<td>□</td>
<td>□</td>
</tr>
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<td>Stroke</td>
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<tr>
<td>Anxiety Disorder</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Human Immunodeficiency Virus (HIV)</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Health Insurance Information:

20. Besides VA health benefits, do you have any other insurance that you use to pay for health services?
   ① Yes
   ② No
   ③ I Don’t Know
Alcohol and Drug Use

This questionnaire asks you about any experience with alcohol or drug use you might have had in your life. You may write in “0” in the lines provided if a question does not apply to you.

Regular use = 3+ times per week, binges, or use in which normal activities are compromised

Alcohol use to intoxication does not necessarily mean “drunk”, and may mean “to feel the effects”, “get a buzz”, or “get high”. As a rule, 3+ drinks in one sitting, or 5+ drinks in one day defines “intoxication”.

Any alcohol use:
1. How many days in the past 30 have you used alcohol (any use at all)? _____
2. How many years in your life have you regularly used alcohol (any use at all)? _____

Alcohol use to intoxication:
3. How many days in the past 30 have you used alcohol (to intoxication)? _____
4. How many years in your life have you regularly used alcohol (to intoxication)? _____

Heroin:
5. How many days in the past 30 have you used heroin? _____
6. How many years in your life have you regularly used heroin _____
   o If you use heroin, how do you usually take it (check all that apply)
     ▪ Orally ___
     ▪ Nasally ___
     ▪ Smoking ___
     ▪ Non-IV Injection ___
     ▪ IV Injection ___

Methadone:
7. How many days in the past 30 have you used methadone? _____
8. How many years in your life have you regularly used methadone? _____
   o If you use methadone, how do you usually take it (check all that apply)
     ▪ Orally ___
     ▪ Nasally ___
     ▪ Smoking ___
     ▪ Non-IV Injection ___
     ▪ IV Injection ___

Opiates/Analgesics (for example: Oxycodone):
9. How many days in the past 30 have you used other opiates/analgesics? _____

10. How many years in your life have you regularly used other opiates/analgesics? 
   - If you use other opiates or analgesics, how to you usually take them (check all that apply)
   - Orally ___
   - Nasally ___
   - Smoothing ___
   - Non-IV Injection ___
   - IV Injection ___

Barbiturates:
11. How many days in the past 30 have you used barbiturates? _____
12. How many years in your life have you regularly used barbiturates? 
   - If you use barbiturates, how to you usually take them (check all that apply)
   - Orally ___
   - Nasally ___
   - Smoothing ___
   - Non-IV Injection ___
   - IV Injection ___

Sedatives/Hypnotics/Tranquilizers (for example: Benzodiazepines, or “Benzos”):
13. How many days in the past 30 have you used sedatives/hypnotics/tranquilizers? _____
14. How many years in your life have you regularly used sedatives/hypnotics/tranquilizers? 
   - If you use sedatives, hypnotics or tranquilizers, how to you usually take them
     (check all that apply)
   - Orally ___
   - Nasally ___
   - Smoothing ___
   - Non-IV Injection ___
   - IV Injection ___

Cocaine:
15. How many days in the past 30 have you used cocaine? _____
16. How many years in your life have you regularly used cocaine?
   - If you use cocaine, how to you usually take it (check all that apply)
   - Orally ___
   - Nasally ___
   - Smoothing ___
   - Non-IV Injection ___
   - IV Injection ___

Amphetamines (for example: Methamphetamine):
17. How many days in the past 30 have you used amphetamines? _____
18. How many years in your life have you regularly used amphetamines? _____
   - If you use amphetamines, how do you usually take it (check all that apply)
     • Orally ___
     • Nasally ___
     • Smoking ___
     • Non-IV Injection ___
     • IV Injection ___

Cannabis or Marijuana:
19. How many days in the past 30 have you used cannabis? _____
20. How many years in your life have you regularly used cannabis? _____
   - If you use cannabis, how do you usually take it (check all that apply)
     • Orally ___
     • Nasally ___
     • Smoking ___
     • Non-IV Injection ___
     • IV Injection ___

Hallucinogens (for example: LSD or mushrooms):
21. How many days in the past 30 have you used hallucinogens? _____
22. How many years in your life have you regularly used hallucinogens? _____
   - If you use hallucinogens, how do you usually take it (check all that apply)
     • Orally ___
     • Nasally ___
     • Smoking ___
     • Non-IV Injection ___
     • IV Injection ___

Inhalants:
23. How many days in the past 30 have you used inhalants? _____
24. How many years in your life have you regularly used inhalants? _____
   - If you use inhalants, how do you usually take it (check all that apply)
     • Orally ___
     • Nasally ___
     • Smoking ___
     • Non-IV Injection ___
     • IV Injection ___

Multiple Substances:
25. How many days in the past 30 have you used more than one substance per day (including alcohol)? _____
26. How many years in your life have you regularly used more than one substance per day (including alcohol)? _____