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Improving Support and Education of Low-Income Baby Boomers Diagnosed with Chronic Hepatitis C Virus Infection through Universal Screening

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Abstract

Aims and objectives—The objective of this study was to identify support needs of low income baby boomers recently diagnosed with chronic hepatitis C virus infection.

Background—The United States Preventive Services Task Force has endorsed one-time screening of all baby boomers (born 1945 to 1965) for hepatitis C because 75% of the estimated 2 to 3 million persons with chronic infection are in this age range. We hypothesized that persons diagnosed by routine screening would have significant psycho-emotional, cognitive, and health care challenges that need to be met by collaborative care and services from nurses and other health care personnel.

Design—Qualitative descriptive study of data from three focus groups with predominantly minority participants (N=16). Data were analyzed using qualitative content analysis, transcribed data were categorized by 3 domains in a previously developed model and a new domain identified in this study. Frequencies of unique participants' comments about each theme were calculated.

Results—Elucidated domains were: 1) psycho-emotional effects due to social stigma, shame, fear, dealing with risky behaviors; 2) social effects due to concerns about infecting others; and 3)

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cognitive deficits because of poor understanding about HCV infection and its care. A new domain related to health care emerged reflecting the following themes: poor access to care, barriers to costly treatment, and navigating complex care for comorbidities. Despite these challenges, participants strongly endorsed universal baby boomer hepatitis C virus screening.

Conclusion—This study describes psycho-emotional and social challenges of people dealing with a hepatitis C diagnosis that are compounded by poor knowledge and barriers to supportive care.

Relevance to clinical practice—Nursing and other allied health personnel require structured support programs to assist older persons diagnosed with hepatitis C with addressing these common challenges with the ultimate goal of achieving a cure.

Keywords

Hepatitis C Virus; Qualitative Research; Patient Navigation; Patient Education; Medically Uninsured

Introduction

The prevalence of hepatitis C virus (HCV) infection globally is estimated to be 2% or about 180 million persons (El-Serag 2012). HCV infection can severely damage the liver, leading to liver failure, and it is a common cause of hepatocellular carcinoma (HCC). Worldwide, the burden of HCC from HCV infection is higher than the prevalence in the United States. For example, in Japan 80–90% of patients with HCC have HCV. In Italy, the prevalence is 44–66%, and 30–50% in the United States, indicating that there is a high rate of long-term consequences from untreated HCV infection (El-Serag 2012). HCV infection is often not diagnosed because it causes few symptoms until late in the course of the disease. In the U.S., millions of Americans have been infected by HCV but less than half have been diagnosed (Centers for Disease Control and Prevention [CDC] 2013). The consequences of failing to diagnose and treat HCV can be severe. In the next two decades, one million Americans are predicted to die from HCV-related complications including cirrhosis, liver failure, and HCC unless treatment is provided (CDC 2012).

In recent years, the dire impact of HCV is being greatly mitigated with the advent of highly effective, well-tolerated anti-HCV therapy. To promote diagnosis and treatment of persons with HCV infection, the U.S. Preventive Services Task Force has endorsed universal HCV screening of baby boomers born from 1945 through 1965 because approximately 80% of all persons with HCV infection in the U.S. are in this birth cohort (Moyer & U.S. Preventive Service Task Force [UTPSTF] 2013). Nationally, diverse inpatient and outpatient settings are implementing these screening guidelines, but these models of care are still relatively sparse (CDC 2013, Coyle *et al.* 2016, Galbraith *et al.* 2015, Tuner et al. 2015A).

Background

A key component of HCV screening, evaluation, and treatment is addressing the educational and support needs of baby boomers who are newly diagnosed with chronic HCV infection through routine screening. Understandably, patients are often distraught when diagnosed

with chronic HCV infection because the diagnosis is usually unexpected and carries substantial stigma (Golden *et al.* 2006). Furthermore, patients need to deal with a complex health care system for evaluation and treatment with costly anti-HCV therapy (Ward & Mermin 2015). To guide education and services to be delivered by nursing and other allied health personnel, a more in-depth understanding is needed of gaps in knowledge and support of persons with newly diagnosed HCV infection, especially those diagnosed through routine baby boomer screening. In particular, education and support should aim to meet the needs of persons who are low income and under or uninsured because they are more likely to have previously undiagnosed HCV based on national data (Fitch *et al.* 2013).

We hypothesized that persons who are newly diagnosed with chronic HCV would have significant need for support related to the impact of this condition on multiple aspects of their lives. To guide our qualitative descriptive study, we examined the content of focus group comments according to a conceptual model developed by Mhatre and colleagues reflecting their review of multiple qualitative studies with HCV-infected persons (Mhatre & Sansgiry 2016). Our analysis focuses on three domains from Mhatre's model: 1) psychological/emotional – reaction to first learning of a HCV diagnosis; 2) social - willingness to share HCV diagnosis with family or friends and their reactions; and 3) cognitive/behavioral - knowledge about HCV and treatment and needed changes in behaviors. However, we added a new domain to focus on the significant barriers presented by the health care system to persons living with HCV infection. Among these challenges is the well described high cost of anti-HCV treatment (Ward & Mermin 2015). Our study participants were recruited from low income, predominantly Hispanic baby boomers diagnosed with chronic HCV through a universal inpatient screening program (Turner et al. 2015B). This qualitative descriptive study offers valuable insights to nurses, other clinicians, health educators, and policymakers regarding opportunities to educate and support low income patients who are newly diagnosed with chronic HCV infection.

Methods

Qualitative descriptive studies follow the principles of naturalistic inquiry. Data can be obtained using open-ended questions from focus group interviews. Focus groups increase an understanding of an issue that has not been well elucidated and have been used to explore challenging topics with minority groups (Morgan 1997, Sandelowski 2000). This approach has the following strengths: 1) exploration and discovery, 2) context and depth, and 3) interpretation (Morgan 1998, p.12).

Participants and setting

Baby boomers (born between 1945 and 1965) who had never been screened or diagnosed with HCV were tested for HCV infection on admission to a safety net hospital in south-central Texas. Details of this program have been previously reported (Turner et al. 2015B). Briefly, the opt-out screening program used posters and flyers to educate patients about United States Preventive Services Task Force recommendations for one-time HCV screening of all baby boomers (Moyer & USPSTF 2013). Admission orders included anti-HCV antibody with reflex HCV RNA tests for never-tested patients. Ninety-five percent of never-

tested patients were screened and HCV RNA testing was performed on 90% of anti-HCV positive test results (Turner et al. 2015A). To educate about HCV infection, a bilingual case manager met with patients who were newly diagnosed and reviewed an interactive, low literacy, educational program in Spanish and English on an electronic tablet device to address: HCV epidemiology, transmission prevention, factors that can accelerate chronic HCV infection, and management/treatment strategies. This app was developed with assistance from Hispanic patient-reviewers about cultural appropriateness and comprehension. Patients not only received personalized counseling while hospitalized, but a bilingual patient navigator also provided telephone support after discharge to address informational needs and barriers to care. Despite this support, we aimed to examine whether patients still had important informational gaps to address.

For this study, we recruited patients who were diagnosed with chronic HCV infection from 12/1/2012 through 8/30/14 and still received case management as of July 2014 to participate in a focus group. Because most of these individuals were uninsured, the lengthy process of evaluating liver disease and accessing HCV treatment through patient assistance programs was still underway.

To recruit participants, a patient navigator contacted patients from July 2014 through September 2014 to explain the study's purpose. Non-English speaking participants were excluded to allow everyone to participate in focus groups conducted in English. Of 42 individuals contacted to participate, 25 (59.5%) consented.

Three focus group meetings were conducted in a research center close to the safety-net hospital from December 2014 through February 2015. We aimed to engage 5–8 participants in each of three focus groups and planned to conduct more if data saturation was not reached. This project was reviewed by the University of Texas Health Science Center at San Antonio's Institutional Review Board. (HSC20150039E).

Data collection—The research team developed an interview guide with open-ended questions addressing key aspects of being diagnosed with HCV infection and living with this disease based on the work of Mhatre and others (Chen *et al.* 2013, Janke *et al.* 2008, Mhatre & Sansgiry 2016, North *et al.* 2014A, North *et al.* 2014B). The questions focused on participants' experiences and challenges with their HCV infection diagnosis, interactions with family and friends, impact on daily life, treatment options, and care for HCV (Table 1). More specific questions asked about reactions to being diagnosed during a hospitalization that was generally for a condition unrelated to HCV. In addition, questions examined participants' understanding of how alcohol use affected liver disease and any change in alcohol consumption since diagnosis.

Each focus group was led by a moderator from the team and observed by at least two team members. The moderator presented a summary at the end of each focus group and conducted a "member check" which is a technique giving participants the opportunity to add or withdraw statements or comments in order to add credibility to the study (Lincoln & Guba 1985). All activities were audiotaped with the consent of participants. Each participant received a \$30 gift card for his/her participation as well as a meal.

Data analysis—Data were analyzed according to qualitative content analysis as described by Elo & Kyngäs for processes of preparation, organization and reporting (Elo & Kyngäs 2008, p.109). Transcripts were initially read in their entirety by four independent research team members, followed by open-coding, and, finally, team members reached a consensus for coding regarding domains and themes within domains that best captured the major experiences and challenges expressed by the participants. Based on the final list of codes, the four team members then recoded each of the three focus group’s transcribed discussions.

Each mention of a previously identified theme by a unique participant was counted by two team members to quantify the numbers of comments, excluding repeated comments by the same person about a theme. Unique members within each focus group commenting about a specific aspect of a theme were totaled and divided by the number of participants in the focus group. Because the three focus groups had different numbers of participants, a weighted average for each theme across the three groups was calculated as reported in Table 2. Larger numbers signify that, across all focus groups, a particular aspect of a theme was mentioned more frequently.

Then the team examined the themes according to domains developed by Mhatre and colleagues. Most themes could be classified within three of the six domains that addressed psycho/emotional, social, and cognitive (behavioral) aspects of living with HCV. However, a new domain emerged that concerned themes related to health care challenges so we added this category to our results.

Results

Of 25 individuals who were recently diagnosed with chronic HCV infection and initially agreed to participate, 16 (64%) attended one of three focus group meetings (range 4 to 7 participants per meeting). Participants’ mean age was 55.3 years (range, 49 to 63) and 3 (19%) were women. Most participants were racial-ethnic minorities, including: 11 (69%) Hispanic, 2 (13%) African American; 2 (13%) Non-Hispanic, and 1 (6%) Arab. Thirteen (81%) participants were uninsured, two (13%) had public insurance, and one (6%) had private insurance.

Dominant themes, categorized by 3 domains from Mhatre’s work and the new domain of health care challenges, are shown in Table 2 along with weighted mean proportions of participants who commented about a theme. Nearly two-thirds of participants addressed topics related to the psychological/emotional impact of the diagnosis, specifically **shame**, stigma, and feeling socially isolated.

“It’s embarrassing to tell somebody. Like they don’t want to touch you.”

“I’d be ashamed to tell them [friends], you know. Basically, because it’s none of their business.”

Another common psychological/emotional theme was **fear** and sense of being overwhelmed when diagnosed with chronic HCV infection, expressed by two-thirds of participants.

“Anyways, when I found out, I was scared, I mean, it was the worst thing I ever heard in my life.”

“They told me, uh, what it was, why this was a dangerous thing. It scared me and I cried and you know, I thought that there wasn’t going to be a cure for it.”

In addition to fear for oneself, over half of the participants expressed **concerns about social contacts** in regard to transmitting the infection. Some described almost being shunned by their family to reduce this risk.

“I was almost like, you know, I wasn’t able to kiss my grandchildren, I wasn’t able to touch them, ...I don’t wanna ruin their lives, you know for whatever mistake I made in my life, and that’s- that’s scary.”

“My wife, it’s just me and my wife, but now I got a special plate, got special glass to drink, to eat, that’s the only thing I use. I be washing my hands all the time, go wash your hands, do this, do that, don’t get out a plate, this is your plate, this is your cup, she doesn’t let me get nothing else.”

In regard to health care services, most participants offered strong support for **universal baby boomer screening**. Lacking this program, most acknowledged that they would have still been unaware of their HCV diagnosis. One participant said that HCV screening should be as widely performed as HIV screening.

“I think everybody should get tested for it. I mean, it is like if you had HIV, don’t they check everybody for that now if you are in the hospital... I thought that was already, you know, Hep C was one of those things [tests] that they do. It’s not?”

“Had I not gone through there, I never would know. Do I think they should keep doing it [screening baby boomers]? Absolutely.”

Another aspect of the psychological/emotional impact of the diagnosis was struggling with possibility of having been infected with HCV because of **behaviors they believed to be risky**.

I think I picked it up from drinking so much. Cause I used to drink a lot of beer and a lot of liquor so in my past- so it disappointed me, you know.”

I remember I got a dirty needle and shared it with the rest of the crowd in there. That was my biggest mistake of my life.”

The majority of focus group members acknowledged having significant barriers to health care because of **lack of insurance**. The cost of anti-HCV medication was also daunting.

“When I didn’t have any insurance, that’s what caused me not to go in unless I was sick. So of course I’m not going to the doctor, like don’t go anywhere or go to the emergency room.

“She told me they had the medication but it cost like up in the thousands of dollars, might as well have been in the million dollars because there’s no way I can afford it”.

Comments about **reducing or stopping alcohol use after learning about HCV diagnosis** were offered by over half of the cohort. However, some subjects were resistant to change.

“...I have to go onto the treatment, and as soon as I start seeing the doctors, I stopped so I stopped drinking, so now especially with this treatment, I can’t. And I know I can do it because I’ve done it before.”

“Um, I was told that I really need to stop drinking but did I stop? No. Why? Because I didn’t feel like it was affecting me.”

Because these patients were diagnosed with HCV during a hospitalization that was usually for another health problem, over 40% acknowledged having psychological/emotional strain because their HCV diagnosis added to **their burden of dealing with other chronic diseases**. Many had little prior contact with health care so they were unaccustomed to receiving long-term care.

“It was all this...when I had the accident, I had high blood pressure, I have this and I have that. They were just hitting me left and right with these things, and I was just- I was just overwhelmed.”

“... I couldn’t do nothing with my back, my bad back. And after I found out I had this [HCV], it would lead one problem to another and sometimes I get scared to go...back to the doctor. It’s just like opening a can of worms, you know...I’ve never had any problems in my life.”

Less commonly, participants discussed the need for **more education about HCV** for themselves and their families. Several participants appreciated opportunity to learn from others during the focus group.

“And then, without being educated I was scared. And I think basically that’s what this whole thing’s about- being educated... We don’t know nothing about it. And then when you do find out, we hear all these taboos without even knowing about it.”

“Uh, can you get it through saliva? Uh, touching? Intercourse? I mean, I need to know how to, uh, not only be a carrier but infect somebody else, you know...I don’t know any of these answers.”

In wrap-up statements, the few persons who had been able to overcome the many barriers to HCV treatment strongly endorsed the value of making this effort.

“And you put up with the side effects, yeah. You wanna be well. You do everything you’re told to, everything is alright. Everything I’m told and with the 12 week treatment and I’m clear. It was worth it, very well worth it.”

Discussion

This qualitative descriptive study of personal experiences and challenges confronted by predominantly uninsured and racial-ethnic minority baby boomers who had been recently diagnosed with HCV infection reveals multiple opportunities to improve education and support from nurses and allied health personnel. As noted by others, the primary impact of

this diagnosis is psychological/emotional because it provokes strong, sometimes devastating reactions of shame, stigma, and fear. In a survey of nearly 300 primarily African-American persons with HCV infection, conducted from 2009 to 2011, nearly 60% reported shame about having the disease and fear about the impact of HCV on their lives (Chen *et al.* 2013). A British focus group study of both HCV-infected patients and the staff treating them, found that these two groups generally had a negative relationship, reflecting in part the demands of managing multiple aspects of this disease (McCreaddie *et al.* 2011). That study found that clinicians were overwhelmed by their large panels of complex patients who needed more support than they could provide. Similarly, in the U.S., baby boomer screening for HCV infection was launched before an evidence-based educational and support program had been developed. Our qualitative study offers a valuable initial guide for nurses and other health care providers to address these unmet educational and support needs of thousands of baby boomers who will be diagnosed with chronic HCV infection through universal screening.

Among the key strategies to help patients with HCV infection is addressing stigma because of associations with undesirable risky behaviors, such as injection needle use, that can lead to HCV infection. Most subjects admitted to worrying about how their lifestyle and substance use behaviors might have resulted in HCV infection. Although it is important to reinforce eliminating risky behaviors such as sharing dirty needles, new analyses of phylogenetic patterns of HCV infection in the U.S. suggested that nosocomial/iatrogenic factors likely played a major role in HCV transmission from the 1940s through 1960s when, for example, patients could have been inadvertently infected because of ineffective sterilization practices (Joy *et al.* 2016). De-stigmatizing how patients acquired HCV can alleviate some of the strain of dealing with this diagnosis and may also reduce the sense of isolation because of being ashamed to share this diagnosis with others.

We observed persistent fear about the impact of the infection on personal health as well as the health of family and other social contacts through potential transmission of HCV. This fear persisted in our patients despite personal counseling and an educational program on a mobile app about HCV, reducing transmission, evaluating effects on the liver, stopping alcohol use, and treatment opportunities developed in collaboration with patients (Turner *et al.* 2015A). However, patients still need substantial support because, in a low income population, access to costly, direct-acting, anti-HCV drugs can be quite challenging. In addition, not only patients, but their families need to understand straightforward approaches to reduce the risk of transmission.

This analysis is novel in studying persons diagnosed through a universal baby boomer screening program in a hospital. Gratifyingly, these patients were strongly supportive of this program and acknowledged that they would otherwise not have known about their HCV infection because many lacked insurance and had not been accessing health care services. These data reinforce the need to extend screening to inpatient settings and emergency departments that serve patients who are not receiving longitudinal care (Galbraith *et al.* 2015). They also reinforce the critical role of nurses who are well attuned to helping patients with behavioral, emotional, and logistical challenges in receiving medical care.

Because our focus group participants were diagnosed when hospitalized, many needed to deal with multiple complex comorbidities and had to navigate a complicated health care system to manage these comorbidities. In our project, we offered education and care navigation by community health workers both in the hospital and longitudinally afterwards to assist with accessing primary and specialty care, as well as completing multiple tests before treatment could be considered (Turner et al. 2015B). That support linked over 80% of newly diagnosed patients to outpatient care for HCV, with over half of these seeing a hepatologist. Other groups have also reported similar benefits to care navigation for persons diagnosed with HCV in sexually transmitted infection clinics, resulting in over 50% receiving HCV care (Falade-Nwulia *et al.* 2016). Community health worker interventions have also significantly improved HCV knowledge in challenging populations such as homeless persons (Tyler *et al.* 2014). Nurses are natural leaders to oversee community health workers.

One of the most difficult aspects of dealing with chronic liver disease for our participants was changing their use of alcohol. Most were able to stop or greatly reduce alcohol consumption but we found that others were more resistant. Offering ongoing counseling and even potentially pharmacologic interventions with that target alcohol use should be a component of any HCV treatment program (North *et al.* 2014B). The inadequacy of this education and support for persons who are newly diagnosed with HCV infection was observed in an international study that observed an increase in alcohol consumption post-notification of an HCV diagnosis among persons with a history of injection drug use (Spelman *et al.* 2015). Counseling programs can be developed to address alcohol consumption because nurses and other health care providers have been shown to be effective in delivering brief alcohol use interventions (Mertens *et al.* 2015).

It should be noted that nurses and other health care providers should not only address the topics noted in this study but also provide education about other essential components of the evaluation and management of this chronic infection including: assessment of the severity of the disease through laboratory testing; understanding of the treatment process; how disease stage affects management plans; complications of chronic HCV infection such as hepatocellular carcinoma that primarily affects persons with cirrhosis; other comorbidities that can affect management of HCV such as hepatitis B infection or that can continue to damage the liver after treatment; and the need to abstain from risky behaviors that can re-infect the patient (Cinar *et al.* 2015, North *et al.* 2014A). Probably one of the most essential roles of a nurse and support team is helping the patient understand that he or she has an excellent opportunity to cure the disease with the new direct acting drugs but only if they are strictly adherent to taking these medications exactly as prescribed. Thus, offering adherence supports and education is a lynchpin of HCV support by nurses and others who are treating this population (Redulla *et al.* 2015).

This study has several limitations to acknowledge. In general, qualitative studies are useful for hypothesis generation but cannot be presumed to offer causal evidence. Nevertheless, our findings echo those of other qualitative studies and extend this research to examine issues confronted by persons diagnosed through universal baby boomer HCV screening. We also offer new data about participants' experiences when dealing with multiple comorbidities in

the context of a challenging healthcare system. Our group of subjects was small but appropriate for focus group studies. We found that, by the third group, we learned few new ideas. Our study subjects were primarily low income Hispanics whose experiences and support needs likely differ from those of other groups. Finally, these patients previously received some education by a community health worker and care navigation so their needs might have been somewhat reduced compared with others who are diagnosed in less supportive settings.

Conclusion

The shame and stigma of HCV were dominant themes from these focus groups with persons newly diagnosed with chronic infection. These reactions to the disease have been cited as contributing to delay in HCV diagnosis of up to 28 years in the United Kingdom (Harris *et al.* 2016) and may also prompt patients to avoid receiving care after diagnosis. Patients and their families also need to be educated about HCV so that the patient diagnosis is not always seen as being due to personal behaviors such as injection drug use because it is now understood to have diverse causes including incidental infection through routine health care decades ago (Joy *et al.* 2016). Furthermore, patients and families need to learn approaches to reduce the risk of transmission and how to change behaviors that can accelerate disease such as alcohol use. Brief alcohol interventions can be effectively administered by nurses (Timko *et al.* 2016). In the U.S., the health care system is uniquely challenging for low income, minority residents because of access, continuity, and coverage issues that must be overcome to achieve a cure for this chronic infection. Culturally appropriate navigation services by nurses has been shown to overcome these challenges for patients with gastrointestinal cancers and can be applied to persons with chronic HCV infection (May *et al.* 2014). Lastly, this study offers strong endorsement of routine baby boomer screening for HCV from participants because of the hope that it can significantly reduce morbidity and mortality from this disease.

Relevance to clinical practice

This study offers unique insights for nurses and other clinicians about the impact of being diagnosed with chronic HCV infection on social interactions with friends and family as well as serious informational gaps and misunderstandings about HCV infection and significant hurdles that these individuals are likely to encounter in receiving care for this potentially curable disease. These are unique additions to the typical topics that should be addressed such as evaluating the stage of disease, treatment plans, and attention to other complications of disease such as hepatocellular carcinoma. This study should galvanize nurses to take the lead in developing educational and support programs that address the myriad of needs of patients newly diagnosed with HCV. Nurses have special expertise in addressing psychosocial complications that can accompany the diagnosis of a potentially serious chronic infection such as depression or anxiety that are especially prevalent in vulnerable populations (Silberbogen *et al.* 2009). The downside for nurses is the time-intensive nature of all of these educational and support needs in addition to addressing behavioral issues such as alcohol consumption. To reduce this burden, nurses can oversee community health workers or potentially even peer educators (Treloar *et al.* 2012) who can offer needed

navigation and support services to help patients negotiate complex care for HCV as well as learning to deal with the many effects of this condition on daily living while understanding a path that can often lead to a cure. However, this infrastructure consumes resources, both in terms of time and money, that must be addressed by policymakers and payers. Yet, the benefits may be significant, if team-based care led by nurses can help patients and their families understand how to deal with and achieve a cure for HCV infection and thereby avert potentially devastating, costly complications.

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References

- Centers for Disease Control and Prevention. Recommendations for the identification of chronic hepatitis C virus infection among persons born during 1945–1965. *Morbidity and Mortality Weekly Report*. 2012; 61:1–32.
- Centers for Disease Control and Prevention. Vital signs: Evaluation of hepatitis C virus infection testing and reporting – Eight U.S. sites, 2005–2011. *Morbidity and Mortality Weekly Report*. 2013; 62:357–361. [PubMed: 23657111]
- Chen EY, North CS, Fatunde O, Bernstein I, Salari S, Day B, Jain MK. Knowledge and attitudes about hepatitis C virus (HCV) infection and its treatment in HCV mono-infected and HCV/HIV co-infected adults. *Journal of Viral Hepatitis*. 2013; 20:708–14. [PubMed: 24010645]
- Cinar S, Ozdogan OC, Alahdab Y. Impact of education provided by nurses on quality of life, anxiety, and depression in patients receiving hepatitis C virus therapy. *Gastroenterology Nursing*. 2015; 38:343–347. [PubMed: 26166422]
- Coyle C, Kwakwa H, Viner K. Integrating routine HCV testing in primary care: Lessons learned from five federally qualified health centers in Philadelphia, Pennsylvania, 2012–2014. *Public Health Reports*. 2016; 131:65–73. [PubMed: 27168664]
- Elo S, Kyngäs H. The qualitative content analysis process. *Journal of Advanced Nursing*. 2008; 62:107–115. [PubMed: 18352969]
- El-Serag H. Epidemiology of viral hepatitis and hepatocellular carcinoma. *Gastroenterology*. 2012; 142:1264–1273. [PubMed: 22537432]
- Falade-Nwulia O, Mehta SH, Lasola J, Latkin C, Niculescu A, O'Connor C, Chaulk P, Ghanem K, Page KR, Sulkowski MS, Thomas DL. Public health clinic-based hepatitis C testing and linkage to care in Baltimore. *Journal of Viral Hepatitis*. 2016; 23:366–74. [PubMed: 26840570]
- Fitch, K., Iwasaki, K., Pyenson, B., Engel, T. Milliman Inc. [accessed June 12, 2016] Health care reform and hepatitis C: A convergence of risk and opportunity. 2013. Available at: <http://us.milliman.com/uploadedFiles/insight/2013/convergence-of-risk-and-opportunity.pdf>
- Galbraith JW, Franco RA, Donnelly JP, Rodgers JB, Morgan JM, Viles AF, Overton ET, Saag MS, Wang HE. Unrecognized chronic hepatitis C virus infection among baby boomers in the emergency department. *Hepatology*. 2015; 61:776–82. [PubMed: 25179527]

- Golden J, Conroy RM, O'Dwyer AM, Golden D, Hardouin JB. Illness-related stigma, mood and adjustment to illness in persons with hepatitis C. *Social Science & Medicine*. 2006; 63:3188–98. [PubMed: 17010490]
- Harris M, Ward E, Gore C. Finding the undiagnosed: a qualitative exploration of hepatitis C diagnosis delay in the United Kingdom. *Journal of Viral Hepatitis*. 2016; 23:479–486. [PubMed: 26924296]
- Janke EA, McGraw S, Garcia-Tsao G, Fraenkel L. Psychosocial issues in hepatitis C: a qualitative analysis. *Psychosomatics*. 2008; 49:494–501. [PubMed: 19122126]
- Joy JB, McCloskey RM, Nguyen T, Liang RH, Khudyakov Y, Olmstead A, Kraiden M, Ward JW, Harrigan R, Montaner JSG, Poon AF. The spread of hepatitis C virus genotype 1a in North America: a retrospective phylogenetic study. *The Lancet Infectious Diseases*. 2016; 16:698–702. [PubMed: 27039040]
- Lincoln, YS., Guba, EG. *Naturalistic inquiry*. Sage Publications; Newbury Park, CA: 1985.
- May M, Woldhuis C, Taylor WK, McCahill LE. Gastrointestinal nurse navigation: implementation of a novel role. *Clinical Journal of Oncology Nursing*. 2014; 18:193–8. [PubMed: 24675254]
- McCreaddie M, Lyons I, Horsburgh D, Miller M, Frew J. The isolating and insulating effects of hepatitis C: a substantive grounded theory. *Gastroenterology Nursing*. 2011; 34:49–59. [PubMed: 21301264]
- Mertens JR, Chi FW, Weisner CM, Satre DD, Ross TB, Allen S, Pating D, Campbell CI, Lu YW, Sterling SA. Physician versus non-physician delivery of alcohol screening, brief intervention and referral to treatment in adult primary care: the ADVISE cluster randomized controlled implementation trial. *Addiction Science & Clinical Practice*. 2015; 1:26.
- Mhatre SK, Sansgiry SS. Development of a conceptual model of health-related quality of life among hepatitis C patients: A systematic review of qualitative studies. *Hepatology Research*. 2016; 46:29–39. [PubMed: 25847330]
- Morgan, DL. *Focus group as qualitative research*. 2. Thousand Oaks, CA: Sage Publications; 1997.
- Morgan, DL. *The focus group guidebook: Focus group kit 1*. Thousand Oaks, CA: Sage Publications; 1998.
- Moyer VA. U.S. Preventive Service Task Force. Screening for hepatitis C virus infection in adults: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*. 2013; 159:349–357. [PubMed: 23798026]
- North CS, Devereaux R, Pollio DE, Hong BA, Jain MK. A) Patient perspectives on hepatitis C and its treatment. *European Journal of Gastroenterology & Hepatology*. 2014; 26:74–81. [PubMed: 23788155]
- North CS, Sims O, Hong BA, Jain MK, Brown G, Lisker-Melman M, Pollio DE. B) An empirical study of alcohol consumption by patients considering HCV treatment. *The American Journal of Drug and Alcohol Abuse*. 2014; 40:484–9. [PubMed: 25140981]
- Redulla RR, Reddy KR, Faust TW, Dudley-Brown S. Project P.E.A.C.H. (Pathway and Educations Towards Adherence and Completion in Hepatitis C Therapy): A nurse-driven evidence-based protocol. *Gastroenterology Nursing*. 2015; 38:369–378. [PubMed: 26422271]
- Sandelowski M. Whatever happened to qualitative description. *Research in Nursing & Health*. 2000; 23:334–340. [PubMed: 10940958]
- Silberbogen AK, Ullola EW, Janke EA, Mori DL. Psychosocial issues and mental health treatment recommendations for patients with hepatitis C. *Psychosomatics*. 2009; 50:114–122. [PubMed: 19377019]
- Spelman T, Morris MD, Zang G, Rice T, Page K, Maher L, Lloyd A, Grebely J, Dore GJ, Kim AY, Shoukry NH, Hellard M, Bruneau J. International Collaborative of Incident HIV and Hepatitis C in Injecting Cohorts (InC3 Study). A longitudinal study of hepatitis C virus testing and infection status notification on behaviour change in people who inject drugs. *Journal of Epidemiology and Community Health*. 2015; 69:745–52. [PubMed: 25814695]
- Timko C, Kong C, Vittorio L, Cucciare MA. Screening and brief intervention for unhealthy substance use in patients with chronic medical conditions: a systematic review. *Journal of Clinical Nursing*. 2016; 25:3131–3143. [PubMed: 27140392]
- Treloar C, Rance J, Laybutt B, Crawford S. Structural constraints on the training of peer educators in hepatitis C prevention. *Health Education Research*. 2012; 27:248–57. [PubMed: 21987474]

Turner BJ, Taylor BS, Hanson JT, Liang Y, Veerapaneni P, Villarreal R, Perez M, Hernandez L, Sandhu J, Fiebelkorn K. High priority for hepatitis C screening in safety net hospitals: Results from a prospective cohort of 4582 hospitalized baby boomers. *Hepatology*. 2015A; 62:1388–95. [PubMed: 26250753]

Turner BJ, Taylor BS, Hanson JT, Perez ME, Hernandez L, Villarreal R, Veerapaneni P, Fiebelkorn K. Implementing hospital-based baby boomer hepatitis C virus screening and linkage to care: strategies, results, and costs. *Journal of Hospital Medicine*. 2015B; 10:510–516. [PubMed: 26033458]

Tyler D, Nyamathi A, Stein JA, Koniak-Griffin D, Hodge F, Gelberg L. Increasing hepatitis C knowledge among homeless adults: results of a community-based, interdisciplinary intervention. *Journal of Behavioral Health Services & Research*. 2014; 41:37–49. [PubMed: 23616250]

Ward JW, Mermin JH. Simple, effective, but out of reach? Public health implications of HCV drugs. *New England Journal of Medicine*. 2015; 373:2678–80. [PubMed: 26575359]

What does this paper contribute to the wider global clinical community?

- From this qualitative descriptive study of persons newly diagnosed with chronic HCV infection, we identify themes of unmet needs to be addressed by nurses and other allied health personnel.
- Support programs need to address: psycho-emotional effects including fear, stigma and shame; changing risky behaviors; lack of knowledge about HCV and its care; and navigating complex health care systems.
- With the advent of universal baby boomer HCV screening, developing team-based systems of care to meet these patients' needs will promote access to curative therapy.

Table 1

Focus Group Guide

<p>What was your reaction to the hepatitis C screening program and learning you were infected?</p> <p>Have you shared your hepatitis C with your family? With your friends?</p> <p>Probe: If not, why not?</p> <p>How has being diagnosed with hepatitis C changed your life?</p> <p>Probe: Have you changed how you drink alcohol?</p> <p>What have been your experiences with receiving care for hepatitis C including treatment for this infection?</p> <p>Of all the things we have talked about, what to you is the most important?</p>
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Table 2

Experiences and Challenges of Persons with Chronic HCV Infection Categorized by Themes within Domains*

<u>Domain Theme</u>	<u>Focus group members addressing theme* (%)</u>
<u>Psychological/emotional</u>	
Shame and social stigma about HCV diagnosis and sharing diagnosis	64.1
Fearful of impact of HCV on health	62.5
<u>Healthcare</u>	
Endorse universal HCV screening of baby boomers	62.5
<u>Social</u>	
Concern about infecting family members and/or other contacts	57.8
<u>Psychological/emotional</u>	
Dealing with possibility that HCV infection resulting from personal risky behaviors	53.1
<u>Psychological/emotional</u>	
Dealing with the need to reduce or eliminate alcohol consumption	53.1
<u>Healthcare</u>	
Lack of insurance, access to care, or barriers to treatment	51.6
<u>Cognitive</u>	
Inadequate personal knowledge about hepatitis C infection	46.9
<u>Health care</u>	
Dealing with managing other comorbidities	42.2
<u>Healthcare</u>	
Educational programs to promote hepatitis C screening	26.6

* Ordered by weighted average from coding by 4 reviewers of 16 participants' comments