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Reducing Barriers to Hepatitis C Treatment among Drug Users: An Integrated Hepatitis C Peer Education and Support Program

Robert J. Roose, MD, MPH, **Lauren Cockerham-Colas, MPH**, **Irene Soloway, R-PA**, **Abigail Batchelder, MPH, MA**, and **Alain H. Litwin, MD, MPH, MS**

Division of Substance Abuse [RJR, LC- C, IS] and the Division of Internal Medicine [AB, AHL] at Albert Einstein College of Medicine in the Bronx

Summary

This report describes an innovative HCV Peer Educator Program that facilitates education, support, and engagement in HCV treatment among patients in an opioid treatment program. Integrating peer educators in a collaborative manner with close supervision holds promise as a model to reduce barriers to HCV treatment among drug users.

Keywords

Hepatitis C; peer education; methadone; opiate agonist treatment; injection drug users

Hepatitis C (HCV) is the most common chronic blood- borne infection in the United States, affecting up to four million people,[1] and is a leading cause of chronic liver disease and cirrhosis. Patients with substance use disorders are disproportionately affected by the burden of chronic HCV and its complications. Despite evidence of successful approaches and national guidelines supporting the treatment of substance users with chronic HCV,[2–5] relatively few have been treated.[6–8] The prevalence of HCV- related complications and liver-related mortality is projected to increase unless treatment patterns change.[9] Provider concerns about poor adherence, adverse effects, high rates of co-morbid alcohol abuse, medical and psychiatric illness, and the risk of re- infection have been cited as reasons to withhold treatment from substance users.[10–11] Substance- using patients also have high rates of poverty, homelessness, incarceration, fragmentation of medical care, mistrust of the medical system, and low levels of social support, all of which can present barriers to care.[12] Patients may also be reluctant to engage in HCV treatment because they believe they do not need it, want more education about it, or have fears about side effects.[13–14] In order to address these complex needs of current and former substance users and best engage them in HCV treatment, the Division of Substance Abuse at Einstein integrated an innovative HCV Peer Education and Support Program into their model of co-located medical and HCV care in an opioid treatment program.[15]

Please address correspondence to Dr. Roose: Providence Behavioral Health Hospital, Sisters of Providence Health System; 1233 Main Street, Holyoke, MA 01040; (413) 302-1614; robert.roose@sphs.com.

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HCV Peer Education and Support Program: History and Background

The Einstein Division of Substance Abuse provides comprehensive treatment for substance use disorders including pharmacotherapy and related services to more than 3,500 adults at three Wellness Centers. Each site provides methadone maintenance, buprenorphine, and intensive outpatient substance abuse treatment with group and individual counseling. Integrated primary medical care, including HIV and HCV treatment, is provided on- site. The clinical staff at each site includes an internist or family physician, physician assistants, a part- time psychiatrist, nurses, and substance abuse counselors. Subspecialty care, advanced diagnostics, and acute care are provided through a linkage with a tertiary care system. The median age of patients is 46 years; 62% of the population is Hispanic, 20% Black, 18% White; and 39% female. More than 250 patients have been treated for HCV on- site since 2001.[15]

Beginning in 2002, HCV support groups were integrated on- site. The groups were developed for patients to discuss and learn about HCV, support one another, and engage with HCV as a community issue. Patients who were treated discussed their experiences and became role models, demonstrating that good outcomes for patients with current or prior substance use were possible. After a year of group activities, staff developed a curriculum for identified patient leaders focusing on HCV knowledge, public speaking, and co-facilitation. Ten of these leaders, called HCV peer educators, completed this process and were given responsibilities, including recruitment for and co-facilitation of support groups, escorting to liver biopsies, providing direct support, and conducting community outreach. Over subsequent years, peer educators were trained with a formalized curriculum and new activities and processes for evaluation and supervision were integrated. This report describes our current HCV Peer Education and Support Program between May 2011 and February 2013. All program- related research was approved by the Institutional Review Board of the Albert Einstein College of Medicine.

Program Goals

The goals of the HCV Peer Education and Support Program are 1) to provide an effective model to educate patients about HCV; 2) to enhance HCV evaluation and treatment services in an opioid treatment program (OTP); and 3) to provide positive activities and ongoing opportunities for skill- based training and community building for patients and peer educators.

Selection and Training of Peer Educators

In 2011 and 2012, we trained 17 peer educators, between 34 and 64 years of age. The majority were men (13), Hispanic (12), and HCV genotype 1 (14). Four peer educators were diagnosed with cirrhosis prior to treatment, and four were co-infected with HIV.

All potential peer educators must have been treated or were currently receiving treatment for HCV, and attended at least one HCV support group in the past. Candidates were identified by program staff and provided a letter describing the responsibilities and training

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requirements of the position and a three- question application.* All candidates submitted an application and attended the orientation session, which provides an overview of the training.

The training curriculum consists of four sessions, each two hours in duration, and a graduation. Session 1 is an introduction to the HCV Peer Education and Support Program where the roles and responsibilities of the position are reviewed and a peer educator agreement is developed collaboratively. Peer educators- in-training practice self-introductions (see explanation in Appendix A, Section 1) and complete a self-refection exercise (Appendix A, Section 2) to help gain a deeper understanding of their desire to become a peer educator. Session 2 focuses on knowledge of HCV. Trainees view the four O.A.S.I.S. "Get the Facts: HCV for IDUs" videos (http://oasiscliniconline.org/8_BOOKS_VIDEOS.html) followed by discussions reviewing key information about HCV, including testing, disease progression, and treatment. Session 3 focuses on outreach skills, public speaking, and confidentiality. Trainees receive instruction on conducting outreach to fellow patients (Appendix A, Section 3) and speaking about HCV in public forums (Appendix A, Section 4). The meaning and importance of confidentiality, including special protections regarding substance abuse treatment, is reviewed, and all trainees sign agreements to protect the confidentiality of patients they interact with (Appendix B). Session 4 consists of performing outreach activities under supervision in order to assess skills, followed by a self- evaluation with program staff (Appendix A, Section 5). To assess HCV knowledge and confidence levels, a 19-question assessment is administered at the beginning and end of the training curriculum. In our two most recent cycles, average HCV knowledge scores increased from 77.5% to 90% with completion of the peer training. Session 5 is a graduation to introduce the new peer educators to the clinic and allow them to tell their personal story publicly regarding HCV. In 2011 and 2012, a total of 17 trainees completed all requirements and graduated as HCV peer educators.

Roles and Responsibilities

HCV peer educators are expected to 1) recruit new patients to engage in HCV- related services on- site through clinic outreach activities; 2) co-facilitate biweekly HCV support and education groups with medical providers; 3) co-facilitate weekly HCV group treatment sessions;[16] 4) escort patients to liver biopsies and other of- site medical appointments; 5) develop and implement peer- led HCV educational programming; and 6) participate in HCV-related community and advocacy activities. Peer educators also attend regular peer educator meetings and represent the HCV program in all clinic-related activities. In an OTP, recruitment of patients by peer educators occurs mostly through direct contact. Most patients receive services daily or several times per week, and it is this feature that informs the structure of our program. It is common to have large numbers of patients with HCV in a single location, as it is the most common co-morbid condition among patients in our clinics. It is thus imperative that peer educators are comfortable speaking openly about HCV and program services. Peer educators are also essential co-facilitators of HCV treatment and support groups. They recruit patients from clinic waiting areas, assist with set-up of the

*1. Why do you want to be a peer educator? 2. Why do you think you would be a good peer educator? 3. Being a peer educator involves ongoing commitment. How many hours per week can you realistically commit to being a Peer Educator?

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room, and welcome patients to the group. They outline ground rules for participation, provide information about HCV, offer support, and discuss their experiences with HCV treatment in concert with the group facilitator. Peer educators also facilitate adherence to off-site appointments by escorting patients. They meet the patient at the facility or travel with the patient from the OTP and stay with them throughout the duration of the appointment. If a patient is not interested in escort services, groups, or other activities with peer educators, they continue to receive services from program staff and providers individually.

Supervision of Peer Educators

Supervision of peer educators is a regular and integral component of the program and provided by a masters- level health professional. Staff facilitates peer educator meetings twice a month to provide ongoing education about HCV, discuss and schedule upcoming activities, brainstorm for future events, troubleshoot any problems, and provide a regular time for mutual support. Additional individual supervision occurs regularly and program staff and peer educators engage in debriefing after each co-facilitated group in order to complete a structured self- evaluation and review what went well and what could be improved.

Peer Educator Stipends and Program Budget

Small monetary stipends ($10– $25) provide incentive for participation and payment to peer educators for their time. Stipends are disbursed according to activities performed and administered monthly. Activities must be scheduled and approved by staff and participation is confirmed before payment. It is important to note that a program does not need a significant budget to be successful. For the first few years of our program we did not have funding and peer educators volunteered their time. Peer educators have emphasized that their participation is not about the money and are rewarded through the gratification they feel in helping others.

Peer Educator Outcomes

From May 2011 to February 2013, 17 peer educators co-facilitated 220 groups and provided 21 escorts to liver biopsies. In all, 200 unique patients attended these groups, and 76 initiated antiviral treatment including 49 with direct- acting antiviral regimens.

Lessons Learned

With nearly 10 years of experience, we believe that our HCV Peer Education and Support Program evolved into an effective model to facilitate the education, support, and engagement of patients in HCV treatment in an OTP. Evidence exists of an informal, yet powerful, “peer pipeline of communication” regarding HCV amongst patients receiving drug treatment that can either hinder or promote initiation of treatment based on the message.[14] We believe it is critical to harness the power of peer communication to promote the treatment of HCV and have identified three factors that we believe are critical for successful implementation.

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Collaboration is essential

Our program is inherently collaborative. Patient feedback was the impetus for starting HCV support groups and, as patients and providers gained more experience, the curriculum became formalized with specific goals. The more we involved peer educators in decision-making, the more engaged they became and took on additional roles or activities. The expectations of being a peer educator and the peer educator agreement (Appendix B) were established together. Throughout the year, peer educators provide feedback on the program and suggest ideas for new activities or opportunities. We believe this type of collaboration results in a sense of ownership in the program and is vital to maintaining active engagement.

Co-facilitation

Integration of peer educators as co-facilitators enhanced our group treatment model and our support and education groups. The presence of a patient who has gone through HCV treatment is a powerful tool in allaying patients' fears and communicating HCV- related information in relatable terms. Peer educators serve as role models and, as they engage in positive activities, help to reduce stigma of HCV and its treatment. The presence of a provider helps ensure that accurate medical information is conveyed, specific medical questions are addressed, and the overall focus is on engaging patients in evaluation and treatment. Co- facilitation allows the expertise of both peers and providers to complement each other and create an atmosphere of trust and collaboration, thereby promoting program efforts throughout the clinic.

Thoughtful peer selection and matching

Peer educators have diverse attributes and skills. It is most effective when program staff knowledgeable about the strengths of each peer educator can assist in assigning activities. For example, we have found that female patients often specifically request a female escort who speaks her primary language for of- site procedures. Some patients even request specific peer educators by name if they have interacted before. It is thus essential to have a cadre of peer educators that represent the diversity of the population served and to allow flexibility in matching peer educators to patients to optimize their engagement in HCV-related care.

Ongoing skill- based training and supervision

As the landscape of HCV treatment rapidly changes, ongoing education is essential for all providers, including peer educators. In our experience, it is most important for training to be practical, participatory, and skill- based rather than focused solely on knowledge. The power of peers is rooted in their personal experience, presence as role models, and effective communication of information. Training should focus on facilitation skills, communication techniques, and self- evaluation and happen at regular intervals to reinforce skills and messages. The level of supervision should match the type of activities performed and be available in the field as well as in the office. Peer educators may have little formal education or work experience and be unfamiliar with position- related expectations. Regular, timely, and consistent supervision is important to identify concerns quickly, support peers in their roles, and reinforce positive behaviors and the expectations of the position.

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Potential Challenges

Working with peer educators as part of a team also presents some unique challenges.

Ensuring confidentiality

Maintaining confidentiality is critical for all patients in health- related programs. Patients with stigmatized conditions, including HIV, HCV, and substance use disorders, present with additional confidentiality requirements. As a result of this, providers in OTPs are familiar with the challenges of ensuring confidentiality and have experience navigating these challenges while providing support or treatment groups. One approach is to place confidentiality as a core ground- rule of all groups in the OTP. Patients are reminded in each group that any personal information shared is to remain in the group. Peer educators are trained in the definition and importance of maintaining confidentiality, including how to speak about health conditions without inquiring about, gathering, or sharing other people's protected health information. All peer educators and patients to receive group HCV treatment sign an agreement to uphold and maintain confidentiality at all times. All groups are co-facilitated by a provider to reinforce the messages, and if at any time confidentiality concerns are raised, they are addressed immediately.

Establishing clear boundaries and roles

In our current model, HCV peer educators are also patients in the OTP and have received treatment for HCV. When patients take on the peer educator role in the clinic, it creates new relationships between peers, medical providers, and program staff, which can challenge previously established relationships. For example, peer educators may want to demonstrate their commitment to the program even in situations where one's health should take priority and they should refrain from participating. Peer educators are not employees and it should be clear that they are patients first and peer educators second. Having non- medical providers, such as a program coordinator or health educator, provide the primary coordination and supervision of peer educators should be considered. It is important that all health care providers are mindful of and clear about their dual role when interacting with peer educators.

Providing opportunities for transition to other roles

In our experience, it is ideal to maintain a balance of experienced and novice peer educators. This allows less experienced peer educators to learn and receive support from more experienced peers. However, as we train new peers each year, there is a limited capacity to have repeat peer educators; and at times it can be challenging to provide opportunities for peer educators to transition to other more professional roles. We have tried to meet this challenge by training and mentoring experienced peer educators for roles outside the program by providing opportunities speaking to community groups or encouraging further educational or vocational training. Two of our highly experienced peer educators have been utilized as consultants for our own HCV program staff. One peer educator was hired as a full- time HCV coordinator for a community agency. A few others started coursework for substance abuse certification. Others assist separate internal programs to provide engagement and linkage services after rapid HCV testing with patients mandated to drug

treatment by court. As more HCV programs incorporate peer educators, we hope it will provide additional opportunities for experienced peer educators to consult, guide, or train other programs.

Recommendations and Future Directions

Current or former substance users present certain challenges for evaluation and treatment of chronic HCV. Many of these barriers can be reduced or overcome by incorporating peer educators with appropriate training and supervision. Becoming a peer educator can also be a transformative experience for the individual. The HCV peer educator position provides an opportunity to engage in positive activities, demonstrate unique skills, and adopt new roles in their treatment center and community—and for some, it has created an upward spiral of positive engagement with health care, community work, and further employment. Systematic evaluations of the impact of HCV peer programs are needed, including how they affect uptake and treatment outcomes, and how different models of peer involvement may suit various settings. Yet given the need for innovative models to address the barriers to HCV treatment, we believe that integrated HCV peer support and education in opioid treatment programs or other settings in which patients frequently congregate, such as residential treatment programs, prisons, or homeless shelters, is one that holds much promise.

Appendix A: Explanation of Peer Educator Training Activities

1. Self-Introductions: The Peer Educator position is a formal role. Thus, Peer Educators need to learn how to formally introduce themselves. During the training sessions, Peer Educators in training practiced introductions in order to become comfortable introducing themselves when representing the HCV Program. The format that we used for self- introductions was:

   > "Hi, my name is [First Name—Last Name]. I am a Hepatitis C Peer Educator in training with the Albert Einstein College of Medicine. My journey with Hep C started when …"

2. Self-Refections: Part of being a Peer Educator involves being able to evaluate one's self and improve one's own knowledge and skills. Peer Educators in training were asked to think about the following questions and share one response with the group:

   1. What do you anticipate liking most in your role as Peer Educator? Liking the least?
   2. Why do you think that you will make a good Peer Educator? What do you think will be most challenging for you?
   3. Do you have any fears about leading a group?

3. Outreach Introductions: Conducting outreach is a significant part of the role of being a Peer Educator. Peer Educators in training were instructed on what to expect when conducting outreach and were given tips on how to conduct effective outreach. Trainees practiced with all necessary materials, including

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clipboards, brochures, and a sign-up sheet for patients who might be interested in receiving services from the HCV program. Their newly learned skills were put into practice during session 4, when they actually conducted outreach for an upcoming HCV Program Orientation.

1. Outreach Tips
   - Remember that your job as a Peer Educator to connect with people
   - Remember to assure confidentiality
   - Be respectful to everyone
   - Remember to listen
2. Talking to Clients
   a. Step1: Ask permission to talk
   b. Step 2: Find a good place to talk
   c. Step 3: Introduce self
      - Name & Title (Hepatitis C Peer Educator)
      - “Are you interested in learning about Hep C?”
      - “Where are you at with Hep C?”
      - Recommend Hep C Orientation (give flyer and/or brochure)
        – Albert Einstein College of Medicine is starting up a new program.
        – Starting new groups:
          ♦ Group Treatment
          ♦ Support & Education Groups
        – “I'll look for you there”

4. Public Speaking: A key component of being a Peer Educator is serving as a representative and advocate for HCV patients and the program as a whole. Therefore, it is important to for Peer Educators to be at least somewhat comfortable with speaking in public. All Peer Educators were required to speak publicly about their personal experience with HCV during the training cycle. Peer Educators were provided with basic tips about how to effectively speak in public, as well as a guideline of what should be included in their speeches. Peer Educators in training were required to practice and perform a mock run for program staff. During this practice, staff provided feedback and guidance about what went well and what could be improved. Final speeches were performed for attendees of the Peer Graduation.

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1. Public Speaking Tips:
    a. (Get their attention! Keep it real! Keep it short! Be yourself! Connect!)
2. Speech Format:
    a. Introduce Self
    b. Pick 3 of the following talking points: 1) How and when I got infected; 2) When I got diagnosed; 3) My Hep C treatment experience; 4) How I think that I can help; 5) Why I am excited about being a Peer Educator; 6) My recovery and Hep C, or 7) What I feel is possible being a Peer.

5. Self-Evaluation: Self-evaluation is an important part of being a Peer Educator. It is important to be able to think about which aspects of the role you do well and which aspects can be improved upon. The following questions were asked of all Peer Educators in Training by the training staff.
    1. What appeals to you most about the Peer Educator program?
    2. What do you want this group to accomplish?
    3. What can we do to help you succeed as a Peer Educator?
    4. What do you see as your role on the Peer Educator team?
    5. How much time can you commit to the Peer Educator program?
    6. *Discussion of speech

Appendix B: HCV Peer Educator Agreement

The team members of the HCV Peer Educator Program will comply with the following agreement:

1. Group Participation Requirements:

    I agree to attend all core peer- training sessions, participate in the group sessions, and respect the other group members. I agree to arrive no later than 15 minutes after the starting time of the group. If I am going to be later than that I will agree to contact the HCV Program Staff and let them know beforehand. I will not sleep or nod during the group. I understand that attending the entire meeting is a requirement for receiving my stipend. Inappropriate behavior during meetings may lead to suspension from the group at the discretion of the staff.

2. Intoxication/Drugs:

    I agree to come to group meetings and scheduled activities unintoxicated, that is, not high on drugs or alcohol nor in such withdrawal that I can not participate appropriately. I understand that if I do come to meetings high I will be asked to leave and I will forfeit my stipend. “High” is defined as intoxicated to the point where participation in the group is negative or disruptive.

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3. Confidentiality:

   It is up to the peer educators to keep personal information to themselves and extremely important to do so or people will not feel free to get support when they need it. Therefore, I agree to keep confidential any personal information shared by group members and clients and I agree to stop any peer educator who is breaching confidentiality by telling me others' personal information. If valid proof of breach exists, the Peer Educator team will impose consequences.

4. Stipend:

   I understand that if I attend all of the core peer training sessions I will receive a stipend of $10/session. I also understand that if I co-facilitate a group or provide a liver biopsy escort and attend a debriefing session with the HCV Program Coordinator that I will receive $25/activity. I will receive $10 per outreach activity, and $10 for each bi-weekly Peer Support meeting that I attend.

5. Absences:

   I understand that I am entitled to 2 excused absences a year. When I am unable to conduct a scheduled activity I agree to contact the HCV Program Staff, giving them at least 1 days notice in order to schedule a replacement peer.

6. Peer Educator Responsibilities:

   As a Peer Educator I agree to attend all of the core peer training sessions and participate in at least 4 activities a year. After each planned activity I agree to attend a debriefing session with the HCV Health Educator within 2 days of the completion of the activity. I agree to attend at least 1 booster training every 6 months.

   Peer educators will report breaches of this contract by fellow peers to the HCV Program Staff. The HCV Program Staff will then meet to address the issue.

   Peer educators will report breaches of this contract by staff to the Medical Director of the Hepatitis C Project (Dr. Alain Litwin or Dr. Robert Roose). If the breach is by the Medical Director, it will be reported to the Division Medical Director.

Name of Peer Educator, printed

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Signature ____

Name of Hepatitis C Program Coordinator, printed

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Signature ____

Date: ____

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Notes

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