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Hepatitis C Medical Case Management

A Targeted Landscape Analysis

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November, 2018

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BACKGROUND

Hepatitis C virus (HCV) is a blood-borne infection that can inflame or damage the liver. Although HCV may be a mild infection for some people, it becomes a chronic, long-term illness for 75-85% of those who contract it.[1] In the U.S., over 3.5 million people have chronic HCV[2]. Acute cases of HCV increased about 3.5-fold from 2010-2016[3] reflecting the highest rates among people who inject drugs.[3,4] Most people newly infected with HCV had exposure to infectious blood through injection drug use suggesting that increases in HCV are related to the U.S. opioid epidemic and corresponding increases in injection drug use and sharing of drug equipment.[4] Currently, HCV causes more deaths than the 60 other reported infectious diseases combined[5] and is the leading cause of liver disease, liver cancer, and liver transplants in the US. With currently available therapies, over 90%[3] of HCV infected individuals can be cured with an 8- to 12-week oral therapy[6]. Some studies now show cure rates approaching 100%.[7]

There is growing interest in interventions to improve the proportion of clients who are successfully linked to care and treated for HCV, and one intervention of interest is medical case management (MCM). MCM contributes to engaging and retaining clients in care throughout the continuum of care process.[8] Medical case managers support clients with HCV by increasing awareness of the need for and access to testing, diagnosis, linkage to care, treatment uptake, adherence to treatment, and, ultimately, viral suppression and cure. This support is critical for vulnerable clients, including people who inject drugs, are marginally housed or homeless, have mental health challenges, are living with HIV, are uninsured or under-insured, and are (or have been recently) incarcerated. Whether delivered in a clinic or community-based organization, MCM and other related services have been used successfully to support people with HCV in overcoming barriers to HCV care and treatment.[9] Strategies include addressing a client's mental health, housing, food benefits, transportation, financial or legal needs, substance use, and other possible barriers to accessing care throughout their movement along the HCV continuum of care.

APPROACH

In March 2018, the Hepatitis Education Project (HEP) engaged Cardea to conduct a literature review and targeted landscape analysis of MCM programs for HCV to inform the development of an: 1) HCV MCM procedure manual for HEP; and 2) HCV MCM toolkit for replication and/or expansion of MCM in Washington State. The landscape analysis included key informant interviews with representatives from organizations providing HCV services, as well as discussions with HEP staff and a review of HEP's MCM forms and data collection system.

Key Informant Interviews

- Hawaii Department of Health
- New York City Department of Health
- Public Health — Seattle & King County
- University of Washington School of Medicine
- Waikiki Health

Using a semi-structured interview guide, Cardea staff conducted key informant interviews with representatives from five organizations identified by HEP as providing quality HCV services in Hawaii, New York, and Washington State. These organizations included state departments of health, county and city programs, a Federally Qualified Health Center, and research study sites. Cardea audiotaped interviews, with permission, to facilitate notetaking and thematic content analysis. Following these interviews, Cardea participated in a two-day site visit to HEP and facilitated in-person meetings with five HEP staff, interviewed one HEP staff member by phone, and reviewed HEP's MCM forms and data collection system.

DIFFERENT TERMS, SIMILAR ROLES

Key informants used a variety of terms when referring to staff providing MCM. Like HEP, some programs use the term "medical case managers" to refer to qualified staff—both licensed and non-licensed—who provide MCM and active referral to a constellation of comprehensive support services, especially for vulnerable populations. These services include support for people with insurance barriers, post-incarceration re-entry challenges, and transportation and other basic needs. Other programs use terms such as "care coordinator" or "patient navigator" to describe staff with similar roles who, depending on the scope of the program, may or may not provide the same level of comprehensive services as HEP. Despite the range of terms, key informants described the same basic aims for MCM—to test, link, and engage clients in HCV-related treatment and care, with the goal of achieving a cure.

Medical Case Managers

- Link and engage clients in medical care
- Support clients in achieving positive health outcomes

FINDINGS AND CONSIDERATIONS

Program Structure

All the key informants underscored the importance of a client-centered, harm reduction approach to whole person care that is non-judgmental, trauma-informed, and stigma-reducing. Key informants also stressed the need to "meet the client where they are" and have a "low threshold" for entrance, engagement, and re-engagement in the program, as needed.

MCM staff included case managers, care coordinators, and patient navigators, and, in some cases, peer navigators. Many key informants prioritized attitudes and skills over formal degrees or licensure in providing this type of quality care. Many noted that HCV-specific content can often be learned more easily than the quality client interaction skills that are critical to building and maintaining rapport, respect, and trust. Key informants emphasized that strong rapport and supportive client interactions were instrumental in providing timely information and education, and targeted support with linkage to care, engagement, and adherence to treatment.

> *"Staff need an approach of respect and meeting patients where they are…other content can be learned."*

Some key informants described MCM that included more frequent client contact and more targeted assistance and support with comprehensive/wraparound services. The average number of client contacts varied greatly, with one program providing about 3-5 contacts per client, while others had 20-30 contacts. The difference in average number of client contacts often reflected how closely affiliated the program was with a health care facility. For example, staff at Public Health—Seattle & King County reported the fewest contacts. However, after meeting the client at a needle exchange program, they were able to "walk with the client to the clinic upstairs" to facilitate linkage to care. Warm handoffs and leveraging resource networks were often cited as strategies for supporting linkage to care and adherence to treatment.

Client outreach and in-reach varied across programs. While some programs used in-reach to identify existing clients through their electronic medical record (EMR) systems and/or benefitted from research project opportunities with additional funding and staffing to meet clients, other programs relied more on traditional outreach. As at HEP, outreach often included snacks and beverages while providing HCV information, education, and testing through numerous community events and partnerships. At HEP, staff conduct outreach in connection with Hepatitis A and B vaccination work, syringe exchange services, and at other venues where potential clients may congregate, including methadone clinics and programs for people who are (or recently have been) incarcerated. HEP staff typically encounter new clients through outreach and partnerships at over 50 outreach sites. Key informants stressed the

importance of these efforts, given that people living with HCV often do not know they are infected, and many do not have access to medical care.

Key informants also described different program components to address client challenges with transportation and clinic hours. These included telehealth consultations with specialists, mobile units, and transportation to appointments, as well as flexible hours.

Considerations

- Determine the scope and focus, as well as staff roles and responsibilities, for MCM to be provided
- Develop and document policies and procedures for creating and/or expanding MCM services, including plans for in-reach and/or outreach, intake and assessment, linkage to care and comprehensive services, engagement in care, and post-treatment support following cure
- Outline plans and approaches for engaging and supporting clients, including provision of point-of-care services, timely phone follow-up, support in getting to scheduled appointments, and strong linkages to clinical or social service facilities
- Foster and maintain strong clinic-based networks, especially if medical evaluation and treatment services are not co-located with the medical case management program

Systems Strengthening

Key informants stressed the importance of building and sustaining relationships with clinics and social services to strengthen MCM, including collaborating and networking with other services and systems such as housing first, wound treatment and other medical care, behavioral health, and justice systems. They noted that interagency collaborative efforts may help in leveraging support across systems to reduce barriers to care (e.g., sobriety tests, insurance challenges, reliance on specialty care instead of utilization of primary care services).

> *"Build personal and institutional relationships with different social services, housing first…facilitates referrals…being available when someone is ready to address behavioral health issues."*

The New York City Department of Health and Mental Hygiene found that cross-systems strengthening can facilitate utilization of more comprehensive services. Suggestions for working across silos included identifying collaborative processes, sharing data and forms, updating appropriate referrals, facilitating warm handoffs and creatively building a synergistic, collaborative approach.[10] Key informants indicated that co-location of services (e.g., syringe exchange, addiction treatment, medical providers, mental health services, pharmacy) with MCM continues to be a strategy to support collaboration and coordination of care. In addition, with improvements in HCV treatment and increased access through primary care, they highlighted the possibilities for greater expansion of case management through care coordination and peer navigation programs.

Many key informants described the importance of considering "client voice" in designing and delivering MCM. For example, most patients surveyed by Waikiki Health identified wound care as their primary need. As a result, Waikiki Health instituted a mobile unit with wound-care services and a newly trained wound-specialist nurse. The mobile unit became an entry point for client engagement and future HCV care.

Training for staff in content and approach to MCM is also important to strengthening MCM. Key informants described training requirements ranging from a minimum three-training certification process to more informal on-the-job training. They mentioned that evidence-based webinars and courses, and coaching and support, were particularly important for new staff. Core skills for staff include how to: 1) provide a client-centered, harm-reduction, low-barrier approach; 2) provide accurate information and follow-up for clients on HCV testing, treatment, and linkage to care; 3) cultivate outreach and linkage to care resources; 4) use data collection and reporting tools effectively; and 5) navigate complex health systems.

The integration of both hepatitis care and other health services for people who inject drugs, increases the number of access points for a client, and supports the effective movement across the continuum of care. Clients benefit by being able to engage in comprehensive, wrap-around services in a single encounter with a medical case manager. To help make this possible, HEP's MCM staff include trained phlebotomists to easily provide blood draws for confirmatory testing on demand, and a nurse on-site that can provide vaccination under a Medical Officer's standing order. The HEP MCM program also has sterile syringes, injection equipment, and naloxone available. Additionally, HEP partners with other agencies to provide HIV testing, opioid agonist therapy (OAT), and mental health services.

For primary care programs that have not previously offered HCV MCM, staff training may result in the ability to increase primary care treatment of HCV and reduce referrals to specialists. As cross-trained staff better understand and build their individual MCM capacity within the broader context of the care team, this system strengthening approach can help to improve quality, integrated care at the point of service.

Considerations

- Build and sustain relationships with primary care providers, drug treatment programs, correctional facilities, and other comprehensive/wraparound services.[11]
- Consider client voice in designing and implementing programs
- Cross-train staff who will be providing MCM, to foster integrated care

Tools, Job Aids, and Forms

Tools, job aids, and forms can be helpful in aligning key messages, promoting client-centered care, guiding and reinforcing quality, and prompting consistent data collection across systems. These resources are particularly helpful when onboarding new staff, rotating staff and providing updates to all staff.

When expanding MSM services, job aids and key forms can help model and reinforce key messages during a scaling-up process, promoting consistency. Among those over-seeing service expansion, or working across different service sites, many key informants stressed the need to have site-specific forms and tools that interface well with their existing systems instead of new and different "generic" tools. In addition, key informants identified the need to consolidate and streamline forms.

> *"After staff are well-trained then you don't need the (job aids and forms) …it's more of a dialog with the patient… and to document services."*

One key informant mentioned that, after staff are well-trained, they often just use these types of resources as reminders and documentation prompts. Staff training should include best practices regarding use of forms, tools, and job aids.

Considerations

- Develop and/or review job aids, tools, and forms, and keep these resources simple, clear, and easy to use
- Review and demonstrate use of job aids, tools, and forms during staff training and supervision

Data Collection, Data Sharing, and Evaluation

Creating a culture and process for sharing data across systems can improve MCM, enhance the client's care plan, and support client engagement and adherence to medical treatment toward cure. For MCM that is not delivered within a medical facility with corresponding client records, data sharing is particularly important for linkage to care, treatment adherence, and follow-up. However, safeguarding private and confidential information, along with ensuring client autonomy and decision-making is key. Data collection and sharing for MCM that is HIPAA compliant may take the form of shared EMR systems, or an agreed upon Release of Information (ROI) signed by the client, authorizing disclosure of health information and enabling the organization to represent them in an effort to access

and coordinate select services and support. Steps must be taken to ensure that the necessary data security and HIPAA-compliant policies and procedures are in place.

> *"Being outside of a medical facility makes EMR access challenging…"*

While programs may want to document and report on fairly consistent data (e.g., number initially tested, number with confirmatory test, number engaged in care, completed treatment, and achieved a sustained viral response for 12 or more weeks after the end of treatment—SVR-12 status) the specific forms, tracking tools, and data management systems vary widely among programs. Key informants indicated that programs benefited from clear, gender-affirming forms that minimize duplication of information requests, are easy for clients to complete, and are easy to input.

Reflecting on the different MCM programs, and the diverse number and type of client contacts, a few respondents identified the desire to measure outcomes over time, to better understand the relative value of different types of client contact and follow up. The use of HCV MCM program evaluation data and reports to show cost and health benefits of getting to HCV cure may be instrumental in increasing awareness and support of local, state, federal, and private funders.

Considerations

- Determine reporting requirements, and consider data collection realities and options
- Tailor forms and data collection to existing systems and needs
- Maximize data sharing by creating and maintaining an ROI with collaborating clinic sites, establishing relationships that facilitate data sharing across systems

Sustainability and the Broader Health Care System

All key informants indicated that program sustainability was important and very challenging. One commented, "It's not well-funded, nationally." When asked about sustainability, one provider mentioned, "That's the million-dollar question!"

> *"Hepatitis C is the neglected step-child…lack of funding… hard to reach patients require multiple contacts… if not funded, it's not sustainable."*

For example, Medicaid reimbursement for HIV-related MCM is often reimbursed differently when compared to HCV-related MCM. Although preventive services like MCM may be recommended by a physician or licensed practitioner for people living with HIV, and subsequently covered under Medicaid even if offered by non-federally qualified health centers, HCV MCM is not currently covered under these circumstances[12]. A change in policy would be helpful to diminish the reliance on grants to provide these essential HCV MCM services.

In some states, insurance payers and/or providers impose requirements that can restrict access to HCV testing and treatment for some clients. Discriminatory state-specific restrictions may include requiring that a client reach a certain stage of liver disease before being eligible for treatment, denying treatment to a client with a history of alcohol or substance use, and/or only allowing certain specialists (who can be hard to access) to prescribe a cure. These types of requirements unnecessarily exclude potential clients from treatment. Knowing about state-specific restrictive practices can help inform HCV MCM implementation strategies and focus advocacy efforts to reduce or eliminate such restrictions.

Key informants noted that it is often easier to fund care coordination than HCV testing, and a common strategy is to seek additional and/or creative funding for needed testing services and use funding from other sources to address overlapping client needs (e.g., Ryan White funding

for clients living with HIV, opioid funding for those who qualify for this type of funding.) Funding constraints have also resulted in staffing and programmatic constraints which led one program to make MCM-related staffing decisions to recruit levels of staff with much lower salary level requirements.

> *"(We) need data to show this population (local correctional facility) is in need of services, and justify the need for a care coordinator."*

To address sustainability issues, many programs have integrated HCV care and treatment funding with other funding sources, including federal and state funding, and 340b programs. Private research grants and pharmaceutical funding were also highlighted as possible funding sources. Key informants stressed the need for increased public sector support to establish and maintain HCV elimination strategies.

Considerations

- Determine sustainability strategies within the context of the scope, practice, and cost of HCV MCM services along with other funding opportunities for broader health services
- Use funding from other sources (e.g., Ryan White, opioid, 340b) and/or other programs, some of which provide case management to similar populations
- Consider a collective impact approach to sustainability, focused on HCV elimination, including identifying and collaborating on a common agenda, shared measurement, mutually reinforcing activities, continuous communications, and governmental back bone support [11]

A summary of themes is included in Appendix 1.

CONCLUSION

The need and opportunity for strengthening HCV MCM programs is growing. Key lessons from this landscape analysis may help inform future operational plans in both medical and non-medical settings. When determining next steps for expanding HCV MCM, the following priority areas were highlighted: 1) integration and strengthening of HCV MCM programmatic components and systems; 2) development of supportive tools and strengthening of data collection, data sharing, and evaluation; and 3) utilization of existing funding streams while strategizing and advocating collectively for increased awareness and support for HCV funding and sustainability.

APPENDIX 1

Key Informant Interview Themes

Themes				
Program Components	**Systems Strengthening**	**Tools, Job Aids and Forms**	**Data Collection and Evaluation**	**Sustainability**
• Client-centered, harm-reduction non-judgmental approach • Low threshold, low barrier services • Strong outreach and/or in-reach • Multiple client contacts • Incorporation of the client's voice into program planning • Linkage to medical evaluation and services • Facilitated client access to comprehensive services • Tailored outreach to impacted populations (IV drug use, marginally housed or homeless, formerly incarcerated, etc.) • Support for transportation • Convenient clinic hours	• Co-location or complimentary nearby services (syringe exchange, addiction treatment, medical providers, mental health services, pharmacist, etc.) • Training certification options (content and approach) • Training for onboarding, cross-training, and regular updates • Task shifting to increase primary care treatment and reduce referrals to specialists • Expansion of client and peer navigation programs • Simplification of processes (with increased access to the more easily tolerated regimens and cure) • Coalition-building partnerships for advocacy, action, and support	• Tailored site-specific forms and processes that build on existing materials • Use of training tools and job aids for onboarding new staff, rotating staff, and incorporating updates on new information • Compatible tools across systems • Consolidation of forms to reduce redundancy and minimize client burden to complete	• Challenges with data sharing across programs • Use of shared ROI • Opportunity to measure outcomes over time, regarding the number and type of client contacts • Utilization of EMRs (EPIC) that pull in client care records from other facilities • System-wide standardized reporting, with flexibility regarding site-specific forms and tracking tools	• Utilization of grant funding from other sources to address overlapping client needs (e.g. opioid and Ryan White HIV funding) • Need for advocacy, policy work, and cost effectiveness data to increase HCV awareness, buy-in and funding (Government and other potential funders) • Challenges state-specific service restrictions (e.g. sobriety, fibrosis stage, prescriber eligibility) • Options for 340b pricing • Some staffing with non-licensed care coordinators to reduce staffing costs • Collective impact efforts for HCV elimination

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