FY 2020 Houston EMA Ryan White Part A/MAI Service Definition
Clinical Case Management

HRSA Service Category Title: **RWGA Only**	**Medical Case Management**
Local Service Category Title:	**Clinical Case Management (CCM)**
Budget Type: **RWGA Only**	**Unit Cost**
Budget Requirements or Restrictions: **RWGA Only**	Not applicable.
HRSA Service Category Definition: **RWGA Only**	***Medical Case Management services (including treatment adherence)*** are a range of client-centered services that link clients with health care, psychosocial, and other services. The coordination and follow-up of medical treatments is a component of medical case management. These services ensure timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Medical case management includes the provision of treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Key activities include (1) initial assessment of service needs; (2) development of a comprehensive, individualized service plan; (3) coordination of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan; and (5) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. It includes client-specific advocacy and/or review of utilization of services. This includes all types of case management including face-to-face, phone contact, and any other forms of communication.
Local Service Category Definition:	**Clinical Case Management**: Identifying and screening clients who are accessing HIV-related services from a clinical delivery system that provides Mental Health treatment/counseling and/or Substance Abuse treatment services; assessing each client's medical and psychosocial history and current service needs; developing and regularly updating a clinical service plan based upon the client's needs and choices; implementing the plan in a timely manner; providing information, referrals and assistance with linkage to medical and psychosocial services as needed; monitoring the efficacy and quality of services through periodic reevaluation; advocating on behalf of clients to decrease service gaps and remove barriers to services helping clients develop and utilize independent living skills and strategies. Assist clients in obtaining needed resources, including bus pass vouchers and gas cards per published HCPHS/RWGA policies.
Target Population (age,	Services will be available to eligible HIV-infected clients residing in

gender, geographic, race, ethnicity, etc.):	the Houston EMA with priority given to clients most in need. All clients who receive services will be served without regard to age, gender, race, color, religion, national origin, sexual orientation, or handicap. Services will target low income individuals with HIV/AIDS who demonstrate multiple medical, mental health, substance use/abuse and psychosocial needs including, but not limited to: mental health counseling (i.e. professional counseling), substance abuse treatment, primary medical care, specialized care, alternative treatment, medications, placement in a medical facility, emotional support, basic needs for food, clothing, and shelter, transportation, legal services and vocational services. Services will also target clients who cannot function in the community due to barriers which include, but are not limited to, mental illness and psychiatric disorders, drug addiction and substance abuse, extreme lack of knowledge regarding available services, inability to maintain financial independence, inability to complete necessary forms, inability to arrange and complete entitlement and medical appointments, homelessness, deteriorating medical condition, illiteracy, language/cultural barriers and/or the absence of speech, sight, hearing, or mobility. *Clinical Case Management* is intended to serve eligible clients, especially those underserved or unserved population groups which include: African American, Hispanic/Latino, Women and Children, Veteran, Deaf/Hard of Hearing, Substance Abusers, Homeless and Gay/Lesbian/Transsexual.
Services to be Provided:	Provision of Clinical Case Management activities performed by the Clinical Case Manager. *Clinical Case Management* is a working agreement between a client and a Clinical Case Manager for a defined period of time based on the client's assessed needs. *Clinical Case Management* services include performing a comprehensive assessment and developing a clinical service plan for each client; monitoring plan to ensure its implementation; and educating client regarding wellness, medication and health care compliance in order to maximize benefit of mental health and/or substance abuse treatment services. The *Clinical Case Manager* serves as an advocate for the client and as a liaison with mental health, substance abuse and medical treatment providers on behalf of the client. The Clinical Case Manager ensures linkage to mental health, substance abuse, primary medical care and other client services as indicated by the clinical service plan. The Clinical Case Manager will perform *Mental Health* and *Substance Abuse/Use Assessments* in accordance with RWGA Quality Management guidelines. Service plan must reflect an ongoing discussion of mental health treatment and/or substance abuse treatment, primary medical care and medication adherence, per client need. *Clinical Case Management is* both office and community-based. Clinical

	Case Managers will interface with the primary medical care delivery system as necessary to ensure services are integrated with, and complimentary to, a client's medical treatment plan.
Service Unit Definition(s): **RWGA Only**	One unit of service is defined as 15 minutes of direct client services and allowable charges.
Financial Eligibility:	Refer to the RWPC's approved *Financial Eligibility for Houston EMA Services*.
Client Eligibility:	HIV-infected individuals residing in the Houston EMA.
Agency Requirements:	*Clinical Case Management* services will comply with the HCPHS/RWGA published Clinical Case Management Standards of Care and policies and procedures as published and/or revised, including linkage to the CPCDMS data system *Clinical Case Management Services* must be provided by an agency with a documented history of, and current capacity for, providing mental health counseling services (categories b., c. and d. as listed under *Amount Available* above) or substance abuse treatment services to PLWH/A (category a. under *Amount Available* above) in the Houston EMA. Specifically, an applicant for this service category must clearly demonstrate it has provided mental health treatment services (e.g. professional counseling) or substance abuse treatment services (as applicable to the specific CCM category being applied for) in the previous calendar or grant year to individuals with an HIV diagnosis. Acceptable documentation for such treatment activities includes standardized reporting documentation from the County's *CPCDMS* or Texas Department of State Health Services' *ARIES* data systems, Ryan White Services Report (RSR), SAMSHA or TDSHS/SAS program reports or other verifiable <u>published</u> data. Data submitted to meet this requirement is subject to audit by HCPHS/RWGA prior to an award being recommended. **Agency-generated non-verifiable data is not acceptable.** In addition, applicant agency must demonstrate it has the capability to continue providing mental health treatment and/or substance abuse treatment services for the duration of the contract term and any subsequent one-year contract renewals. Acceptable documentation of such continuing capability includes <u>current</u> funding from Ryan White (all Parts), TDSHS HIV-related funding (Ryan White, State Services, State-funded Substance Abuse Services), SAMSHA and other ongoing federal, state and/or public or private foundation HIV-related funding for mental health treatment and/or substance abuse treatment services. Proof of such funding must be documented in the application and is subject to independent verification by HCPHS/RWGA prior to an award being recommended. Loss of funding and corresponding loss of capacity to provide mental health counseling or substance abuse treatment services as applicable may result in the termination of Clinical Case Management Services

	awarded under this service category. Continuing eligibility for Clinical Case Management Services funding is explicitly contingent on applicant agency maintaining verifiable capacity to provide mental health counseling or substance abuse treatment services as applicable to PLWH/A during the contract term. **Applicant agency must be Medicaid and Medicare Certified**.
Staff Requirements:	Clinical Case Managers must spend at least 42% (867 hours per FTE) of their time providing direct case management services. Direct case management services include any activities with a client (face-to-face or by telephone), communication with other service providers or significant others to access client services, monitoring client care, and accompanying clients to services. Indirect activities include travel to and from a client's residence or agency, staff meetings, supervision, community education, documentation, and computer input. Direct case management activities must be documented in the Centralized Patient Care Data Management System (CPCDMS) according to CPCDMS business rules. *Must comply with applicable HCPHS/RWGA Houston EMA/HSDA Part A/B Ryan White Standards of Care:* Minimum Qualifications: **Clinical Case Managers** must have at a minimum a Bachelor's degree from an accredited college or university with a major in social or behavioral sciences and have a current and in good standing State of Texas license (LBSW, LSW, LMSW, LCSW, LPC, LPC-I, LMFT, LMFT-A or higher level of licensure). The Clinical Case Manager may supervise the Service Linkage Worker. CCM targeting Hispanic PLWHA must demonstrate both written and verbal fluency in Spanish. Supervision: The **Clinical Case Manager** (CCM) must function with the clinical infrastructure of the applicant agency and receive supervision in accordance with the CCM's licensure requirements. At a minimum, the CCM must receive ongoing supervision that meets or exceeds HCPHS/RWGA published Ryan White Part A/B Standards of Care for Clinical Case Management. If applicant agency also has Service Linkage Workers funded under Ryan White Part A the CCM may supervise the Service Linkage Worker(s). Supervision provided by a CCM that is not client specific is considered **indirect time** and is not billable.
Special Requirements: **RWGA Only**	Contractor must employ full-time Clinical Case Managers. Prior approval must be obtained from RWGA to split full-time equivalent (FTE) CCM positions among other contracts or to employ part-time staff. **Contractor must provide to RWGA the names of each Clinical Case Manager and the program supervisor no later than 3/30/17. Contractor must inform RWGA in writing of any**

	changes in personnel assigned to contract within seven (7) business days of change. Contractor must comply with CPCDMS data system business rules and procedures. Contractor must perform CPCDMS new client registrations and registration updates for clients needing ongoing case management services as well as those clients who may only need to establish system of care eligibility. Contractor must issue bus pass vouchers in accordance with HCPHS/RWGA policies and procedures.

FY 2023 RWPC “How to Best Meet the Need” Decision Process

Step in Process: **Council**		Date: **06/09/2022**
Recommendations:	Approved: Y:_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: **Steering Committee**		Date: **06/02/2022**
Recommendations:	Approved: Y:_____ No: ______ Approved With Changes:______	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: **Quality Improvement Committee**		Date: **05/03/2022**
Recommendations:	Approved: Y:_ ___ No: ______ Approved With Changes: _______	If approved with changes list changes below:
1.		
2.		
3.		
Step in Process: **HTBMTN Workgroup #1**		Date: **04/19/2022**
Recommendations:	Financial Eligibility:	
1.		
2.		
3.		

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Public Health
Building a Healthy Community

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FY 2020 PERFORMANCE MEASURES HIGHLIGHTS

RYAN WHITE GRANT ADMINISTRATION

HARRIS COUNTY PUBLIC HEALTH (HCPH)

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Summary Reports for all Services

Highlights from FY 2020 Performance Measures

Measures in this report are based on the *2021-2022 Houston Ryan White Quality Management Plan*, *Appendix B. HIV Performance Measures*. The document can be referenced here: https://publichealth.harriscountytx.gov/Services-Programs/Programs/RyanWhite/Quality

Clinical Case Management

- During FY 2020, from 3/1/2020 through 2/28/2021, 1,046 clients utilized Part A clinical case management. According to CPCDMS, 580 (56%) of these clients accessed primary care two or more times at least three months apart during this time period after utilizing clinical case management.
- Among these clients, 46% accessed mental health services at least once during this time period after utilizing clinical case management.
- For clients who have lab data in CPCDMS, 73% were virally suppressed.

Ryan White Part A
HIV Performance Measures
FY 2020 Report

Clinical Case Management
All Providers

For FY 2020 (3/1/2020 to 2/28/2021), 1,046 clients utilized Part A clinical case management.

HIV Performance Measures	FY 2019	FY 2020	Change
A minimum of 75% of clients will utilize Part A/B/C/D primary care two or more times at least three months apart after accessing clinical case management	732 (56.4%)	580 (55.5%)	**-0.9%**
35% of clinical case management clients will utilize mental health services	413 (31.8%)	485 (46.4%)	**14.6%**
80% of clients for whom there is lab data in the CPCDMS will be virally suppressed (<200)	548 (80.2%)	381 (73.3%)	**-6.9%**
Less than 5% of clients will be homeless or unstably housed	142 (10.9%)	98 (9.4%)	**-1.5%**

According to CPCDMS, 13 (1.2%) clients utilized primary care for the first time and 84 (8.0%) clients utilized mental health services for the first time after accessing clinical case management.

Clinical Chart Review Measures	FY 2019
85% of clinical case management clients will have a case management care plan developed and/or updated two or more times in the measurement year	7%
Percentage of clients identified with an active substance abuse condition referred to substance abuse treatment	*100%

*Of the 26 clinical case management clients with active substance use disorder, all 26 (100%) received a referral for further treatment.

Harris County
Public Health
Building a Healthy Community

Ryan White Part A
Quality Management Program- Houston EMA
Case Management Chart Review FY 2020-21
Ryan White Grant Administration

CUMMULATIVE SUMMARY, DE-IDENTIFIED

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Overview

Each year, the Ryan White Grant Administration Quality Management team conducts chart review in order to continuously monitor case management services and understand how each agency implements workflows to meet quality standards for their funded service models. This process is a supplemental complement to the programmatic and fiscal audit of each program, as it helps to provide an overall picture of quality of care and monitor quality performance measures.

A total of 624 medical case management client records were reviewed across seven of the ten Ryan White-Part A funded agencies, including a non-primary care site that provides Clinical Case Management services. The dates of service under review were March 1, 2020- February 28, 2021. The sample selection process and data collection tool are described in subsequent sections.

Case Management is defined by the Ryan White legislation as a, “range of client-centered services that link clients with health care, psychosocial, and other services,” including coordination and follow-up of medical treatment and “adherence counseling to ensure readiness for and adherence to HIV complex treatments.” Case Managers assist clients in navigating the complex health care system to ensure coordination of care for the unique needs of People Living With HIV. Continuous assessment of need and the development of individualized service plans are key components of case management. Due to their training and skill sets in social services, human development, psychology, social justice, and communication, Case Managers are uniquely positioned to serve clients who face environmental and life issues that can jeopardize their success in HIV treatment, namely, mental health and substance abuse, poverty and access to stable housing and transportation, and poor social support networks.

Ryan White Part-A funds three distinct models of case management: Medical Case Management, Non-Medical Case Management (or Service Linkage Work), and Clinical Case Management, which must be co-located in an agency that offers Mental Health treatment/counseling and/or Substance Abuse treatment. Some agencies are also funded for Outreach Services, which complement Case Management Services and are designed to locate and assist clients who are on the cusp of falling out of care in order to re-engage and retain them back into care.

The Tool

A copy of the Case Management Chart Review tool is available in the Appendix of this report.

The Case Management Chart Review tool is a pen and paper form designed to standardize data collection and analysis across agencies. The purpose of the tool is to capture information and quantify services that can present an overall picture of the quality of case management services provided within the Ryan White Part-A system of care. This way, strengths and areas of improvement can be identified and continuously monitored.

The coversheet of the chart abstraction tool captures basic information about the client, including their demographics, most recent appointments, lab results, and any documented psychological, medical, or social issues or conditions that would be documented in their medical record.

The content of the second sheet focuses on coordination of case management services. There is space for the chart abstractor to record what type of worker assisted the client (Medical Case Manager, Service Linkage Worker, Outreach Worker or Clinical Case Manager) and what types of services were provided. It is expected that any notes about case management closure are recorded, as well as any assessments or service plans or documented reasons for the absence of assessments or service plans.

The Sample

In order to conduct a thorough and comprehensive review, a total of 624 client records were reviewed across seven agencies for the 2020-2021 grant year. This included sixty-one (61) Clinical Case Management charts at a non-primary care site. In this Case Management Chart Review Report, any section that evaluated a primary care related measure excludes the sample of the non-primary care site. Minimum sample size was determined in accordance with *Center for Quality Improvement & Innovation* sample size calculator based on the total eligible population that received case management services at each site.

Agency	A	B	C	D	E	F	G
# of Charts Reviewed	79	85	91	105	105	98	61

TOTAL 624 (563 excluding non-Primary Care site)

For each agency, a randomized sample of clients who received a billable Ryan White- A service under at least one (1) of eleven (11) case management subcategory codes during the March 1, 2020- February 28, 2021 grant year was queried from the Centralized Patient Care Data Management System database. Each sample was determined to be comparable to the racial, ethnic, age, and gender demographics of each site’s overall case management patient population.

Cumulative Data Summaries

APPOINTMENTS & ENCOUNTERS

The number of HIV-related primary care appointments and case management encounters in the given year were counted for each client.

HIV-RELATED PRIMARY CARE APPOINTMENTS

For this measure, the number of face-to-face encounters and virtual telehealth visits for an HIV-related primary care appointment with a medical provider was counted. Each encounter was assessed for a minimum of 3 medical appointments. Any Viral Load that accompanied the appointment was also recorded.

HIV MEDICAL # appt	**A**	**B**	**C**	**D**	**E**	**F**	**TOTAL**	**PERCENT**
0	1	4	11	31	8	4	59	**10%**
1	5	23	9	40	42	10	129	**23%**
2	18	27	10	26	38	15	134	**24%**
3	55	31	61	8	17	69	241	**43%**
Total	*79*	*85*	*91*	*105*	*105*	*98*	*563*	

The overall sample trends towards a higher number of primary care appointment in the year, with most of the case management review clients having at least 3 appointments in the year (43%), followed by (24%) of the clients having 2 appointments in the year.

CASE MANAGEMENT ENCOUNTERS

Frequency of case management encounters were also reviewed. The number and types of the encounters (face-to-face vs. phone), as well as who provided the service (Clinical, Medical, or Non-Medical Case Manager) were also recorded.

The distribution of frequency of case management encounters could be described as evenly distributed across encounters.

CASE MGMNT # appointments	**A**	**B**	**C**	**D**	**E**	**F**	**G**	**TOTAL**	**PERCENT**
1	19	23	17	35	19	32	8	153	**25%**
2	21	17	13	12	30	23	6	122	**20%**
3	9	10	12	12	22	24	15	104	**17%**
4	17	19	16	22	10	10	13	107	**18%**
5	13	16	33	24	24	9	19	138	**22%**
Total	*79*	*85*	*91*	*105*	*105*	*98*	*61*	*624*	

VIRAL SUPPRESSION

Any results of HIV Viral Load laboratory tests that accompanied HIV-related primary care appointments were recorded as part of the case management chart abstraction. Up to three laboratory tests could be recorded. Lab results with an HIV viral load result of less than 200 copies per milliliter were considered to be virally suppressed.

Upon coding, clients who were suppressed for all of their recorded labs (whether they had one, two, or three tests done within the year), were coded as "Suppressed." Clients who were unsuppressed (>200 copies/mL) for all of their labs were coded as "Unsuppressed." Clients who had more than one laboratory test done and were suppressed for at least one and unsuppressed for at least one were coded as "Mixed Status," and clients who had no laboratory tests done within the entire year were coded as "Unknown."

SUPPRESSION STATUS	A	B	C	D	E	F	TOTAL	PERCENT
Suppressed for all labs	32	31	43	72	72	33	283	**50%**
Mixed status	0	0	0	3	10	0	13	**2%**
Unknown (no recent labs on file)	44	51	37	21	10	55	218	**39%**
Unsuppressed for all labs	3	3	11	9	13	10	49	**9%**
Total	*79*	*85*	*91*	*105*	*105*	*98*	*563*	

Across all primary care sites, the case management clients reviewed for these samples had a viral load suppression rate of 50%. In contrast, this result is much lower than what is typical for the Ryan White Part A Houston Primary Care Chart review, which has hovered around 85% for the past several years. This difference may be due to several factors, mainly the Covid-19 pandemic and reduction of in-person labs due to telehealth visits. The Primary Care chart review sample is collected from a pool of clients who are considered *in care*, or have at least two medical appointments with a provider with prescribing privileges in the review year. Additionally, "fluctuating viral load" is one of the eligibility criteria for medical case management, so clients who have challenges maintaining a suppressed viral load are more likely to be seen by case management and be included in this sample.

CARE STATUS

The chart abstractor also documented any circumstances in the record for which a client was new, lost, returning to care, or some combination of those care statuses. A client was considered "New to Care," if they were receiving services for the first time at that particular agency (not necessarily new to HIV treatment or the Houston Ryan White system of care). "Lost to Care" was defined as not being seen for an HIV-related primary care appointment within the last six months and not having a future appointment scheduled, even beyond the review year. "Re-engaged in Care" was defined as any client who was previously lost to care, either during or before the review year, and later attended an HIV-related primary care appointment.

CARE STATUS	**A**	**B**	**C**	**D**	**E**	**F**	**TOTAL**	**PERCENT**
New to Care	11	5	11	1	2	5	35	**6%**
Lost to Care	11	2	1	15	11	2	42	**7%**
Re-engaged in Care	0	0	0	1	0	0	1	**1%**
Both New and later Lost to Care in the same review year	8	2	20	3	17	15	65	**12%**
Re-engaged and later lost again	0	0	0	1	1	0	2	**<1%**
N/A	49	76	59	84	74	76	418	**74%**
Total	*79*	*85*	*91*	*105*	*105*	*98*	*563*	

Overall, 6% of the sample was considered New to Care, 7% was Lost to Care, and <1%was Re-engaged in Care.

When a client's attendance met one of the above care statuses, their medical record was reviewed to understand if case management or other staff was involved in coordinating their care. Activities that counted as "Coordination of Care" were any actions that welcomed the client into or back into care or attempted to retain them in care, such as: reminder phone calls, follow-up calls, attendance, or introduction at the first appointment, or home visits.

COMORBIDITIES

To understand and document common comorbidities within the Houston Ryan White system of care, co-occurring conditions were recorded, including mental health and substance abuse issues, other medical conditions, and social conditions. This inventorying of co-morbidities may prove particularly helpful for selecting future training topics for case management staff.

MENTAL HEALTH & SUBSTANCE USE DISORDER (history or active)

Any diagnosis of a mental health disorder (MH) or substance use disorder issue (SUD) was recorded in the chart review tool, including a history of mental illness or substance use. All Electronic Medical Records include some variation of a "Problem List" template. This list was often a good source of information for MH and SUD diagnoses, but providers sometimes also documented diagnoses or known histories of illness within progress notes without updating the Problem List. Clients sometimes also self-reported that they had been diagnosed with one of the below conditions by a previous medical provider. Any indication of the presence of mental illness or SUD, regardless of where the information was housed within the medical record, was recorded on the chart abstraction tool. Clients could also have or have had more than one of the MH or SUD issues. Any conditions other than alcohol misuse, other SUD, depression, bipolar disorder, anxiety, or schizophrenia were recorded as "Other." The most common types of condition coded as "Other" was Post-Traumatic Stress Disorder.

Diagnosis or Issue	A	B	C	D	E	F	G	TOTAL	PERCENT
Alcohol abuse/dependence	3	2	5	1	13	6	20	50	**9%**
Other Substance dependence	14	1	5	0	15	7	19	61	**10%**
Depression	16	11	32	14	42	33	37	185	**32%**
Bipolar disorder	6	5	7	1	5	10	14	48	**8%**
Anxiety	9	12	14	51	28	22	32	168	**29%**
Schizophrenia	1	1	0	14	1	2	7	26	**4%**
Other	2	0	11	2	12	9	10	46	**8%**

Overall, 93% of the sample had either an active diagnosis or history of a mental health or substance abuse issue documented somewhere within their medical record. This is inclusive of the Clinical Case Management site, for which diagnosis with or clinical indication of a MH or SUD issue is an eligibility criteria.

MENTAL HEALTH & SUBSTANCE USE DISORDER REFERRALS

For clients with an *active* diagnosis of a mental health or SUD issue, the chart abstractor recorded if they were referred or already engaged in MH/SUD services.

MH referral	A	B	C	D	E	F	TOTAL	PERCENT
N/A	75	82	55	100	97	88	497	**88%**
Yes	3	3	13	5	8	10	42	**7%**
No	1	0	23	0	0	0	24	**4%**
Total	82	85	91	105	105	98	563	

Overall, 88% of the sample would not have been appropriate for a MH or SUD referral based on the information available in their medical record. An additional 7% either did receive a referral or were already engaged in treatment and 4% did not receive a referral.

MEDICAL CONDITIONS

Medical conditions other than HIV were also recorded in an effort to understand what co-occurring conditions may be considered commonly managed alongside HIV within the case management population. Sexually Transmitted Infections and Hypertension were common, at 33% and 25% prevalence within the sample, respectively. The site visit tool does not list obesity as a medical condition however, obesity was the most common co-occurring condition that was coded in the “Other” category.

Medical Condition	A	B	C	D	E	F	TOTAL	PERCENT
Smoking (hx or current)	10	7	12	11	33	10	83	**16%**
Opportunistic Infection	0	0	3	6	0	0	9	**2%**
STIs	38	16	48	3	39	31	175	**33%**
Diabetes	5	11	8	4	20	22	70	**13%**
Cancer	0	3	1	6	0	1	11	**2%**
Hepatitis	7	5	1	7	9	9	38	**7%**
Hypertension	12	37	21	11	22	28	131	**25%**
Other	2	3	5	0	8	1	19	**4%**

SOCIAL CONDITIONS

Any indication within the medical record that a client had experienced homelessness/housing-related issues, pregnancy/pregnancy-related issues, a release from jail or prison, or intimate partner violence at any point within the review year was recorded in the chart abstraction tool. Homelessness and housing issues were the most commonly identified "Social Condition" within the sample.

Social Issue	A	B	C	D	E	F	G	TOTAL	PERCENT
Homelessness or housing-related issues	5	0	3	4	15	1	10	38	**6%**
Pregnancy or pregnancy-related issues	6	2	0	0	0	0	0	8	**1%**
Recently released	0	0	1	0	2	0	0	3	**<1%**
Intimate Partner Violence	3	0	0	0	5	0	10	18	**2%**

COMPREHENSIVE ASSESSMENTS

A cornerstone of service provision within case management is the opportunity for the client to be formally assessed at touchpoints throughout the year for their needs, treatment goals, and action steps for how they will work with the case manager or care team to achieve their treatment goals. Agencies need to use an approved assessment tool and service plan, which may either be the sample tools available through Ryan White Grant Administration or a pre-approved tool of the agency's choosing.

The Ryan White Part-A Standards for medical case management state that a comprehensive assessment should be completed with the client at intake and that they should be re-assessed at least every six months for as long as they are receiving medical case management services. A more formal, comprehensive assessment should be used at intake and annually, and a brief reassessment tool is sufficient at the 6-month mark. In other words, the ideal standard is that every client who receives case management services for an entire year should have at least two comprehensive assessments on file. A service plan should accompany each comprehensive assessment to outline the detailed plan of how the identified needs will be addressed with the client.

# of Comp assessments	A	B	C	D	E	F	G	TOTAL	PERCENT
0	62	85	78	100	89	83	0	497	**79%**
1	17	0	13	3	16	15	15	79	**13%**
2	0	0	0	2	0	0	9	11	**2%**
N/A	0	0	0	0	0	0	37	37	**6%**
Total	79	85	95	105	105	98	61	624	

The client was considered "N/A" for a comprehensive assessment if they did not work with a medical case manager throughout the year. As outlined above, 6% of the sample did not work with a Medical Case Manager within the year. 79% of the sample received zero comprehensive assessments, 13% received one, and 2% received two.

SERVICE PLANS

As mentioned, each comprehensive assessment should be accompanied by a service plan, otherwise known as a care plan, to outline what action(s) will be taken to address the needs identified on the comprehensive assessment. A service plan can be thought of as an informal, working, contract between client and social worker for accountability of needed actions, and in what order, to meet a client's determined treatment goals. As with the comprehensive assessment, each completed service plan was recorded in the chart abstraction tool, along with any documented justification for why a service plan was missing if it should have been completed.

# of service plans	A	B	C	D	E	F	G	TOTAL	PERCENT
0	65	82	91	102	95	98	7	540	**87%**
1	14	3	0	2	10	0	10	39	**6%**
2	0	0	0	1	0	0	7	8	**1%**
N/A	0	0	0	0	0	0	37	37	**6%**
Total	79	85	91	105	105	98	61	624	

It is notable that less service plans are completed than comprehensive assessments, even though the two processes are intended to occur together, one right after the other. RWGA experienced a transition in CM chart review auditors midway through the chart review process. As a result, it is unclear what the criteria for determining a client was "N/A" at agency "G".

BRIEF ASSESSMENTS

Like Medical Case Management, Non-Medical Case Management is guided by a continuous process of ongoing assessment, service provision, and evaluation. Clients should be assessed at intake using a Ryan White Grant Administration approved brief assessment form and should be reassessed at six-month intervals if they are still being serviced by a Non-Medical Case Manager.

# of Brief assessments	A	B	C	D	E	F	TOTAL	PERCENT
0	52	73	55	56	30	80	346	**61%**
1	24	12	34	38	54	18	180	**33%**
2	3	0	2	7	1	0	13	**2%**
N/A	0	0	0	4	20	0	24	**4%**
Total	79	85	91	105	105	98	563	

Completion of brief assessments were recorded. 4% of the sample would not been applicable for a brief assessment, as they did not receive services from a Non-Medical Case Manager. 61% of the sample received zero brief assessments, 33% received one, and 2% received two.

ASSESSED NEEDS

All data from assessment tools was captured in the chart review tool. A total of 624 Comprehensive Assessments and 563 Brief Assessments were reviewed and recorded to quantify the frequency of needs. The count recorded is a raw count of how many times a need was recorded, encompassing both comprehensive and brief assessments and including clients who may have had the same need identified more than once at different points in time.

The most frequently assessed needs were: 1) Medical/Clinical, 2) Dental Care, 3) Vision Care, 4) Medication Adherence Counseling, 5) Mental Health, and (6) Insurance. It should be noted, however, that there are no universal standards or instructions across case management systems on how to use these tools or how these needs are defined. Anecdotally, some case managers reported that they automatically checked "Medical/Clinical" and "Medication Adherence Counseling" as a need, regardless of whether or not the client needed assistance accessing medical care, because it was their understanding that this section *always* needed to be checked in order to justify billing for medical case management services. Therefore, this compilation of comprehensive and brief assessments should not be considered representative of *true need* within the HIV community in Houston, but rather, as representative of issues that case managers are discussing with clients.

Need identified on assessment	A	B	C	D	E	F	G	TOTAL	PERCENT
Medical/Medication	42	12	41	37	24	35	8	199	**8%**
Vaccinations	10	7	0	44	22	0	6	89	**4%**
Nutrition/Food Pantry	10	8	16	0	18	1	4	57	**3%**
Dental	31	11	18	16	29	14	8	127	**5%**
Vision	19	11	31	12	14	13	5	105	**4%**
Hearing Care	15	9	26	1	0	12	1	64	**3%**
Home Health Care	10	3	8	0	1	2	0	24	**1%**
Basic Necessities/Life Skills	41	9	28	4	5	32	5	124	**5%**
Mental Health	33	9	45	16	24	44	14	185	**7%**
Substance Use Disorder	43	12	37	4	5	35	6	142	**6%**
Abuse	27	11	17	1	12	15	2	85	**4%**
Housing/Living Situation	41	12	35	9	10	34	8	149	**6%**
Support Systems	47	12	42	3	3	33	1	141	**6%**
Child Care	14	6	4	0	0	4	0	28	**1%**
Insurance	52	11	31	3	9	46	4	156	**6%**
Transportation	36	12	55	11	6	35	6	161	**6%**
HIV-Related Legal Assistance	25	8	21	0	1	27	0	82	**3%**
Cultural/Linguistic	28	1	12	0	0	20	0	61	**3%**
Self-Efficacy	40	1	12	0	0	40	4	97	**4%**
HIV Education/Prevention	21	12	40	3	4	36	0	116	**5%**
Family Planning/ Safer Sex	9	11	7	0	4	2	1	34	**2%**
Employment	39	7	39	0	4	33	4	126	**5%**
Education/Vocation	35	10	30	0	0	10	0	85	**4%**
Financial Assistance	8	10	12	21	15	8	13	87	**4%**
Medication Adherence Counseling	44	9	43	19	27	43	17	182	**7%**
Client Strengths	1	0	0	1	0	0	3	5	**1%**

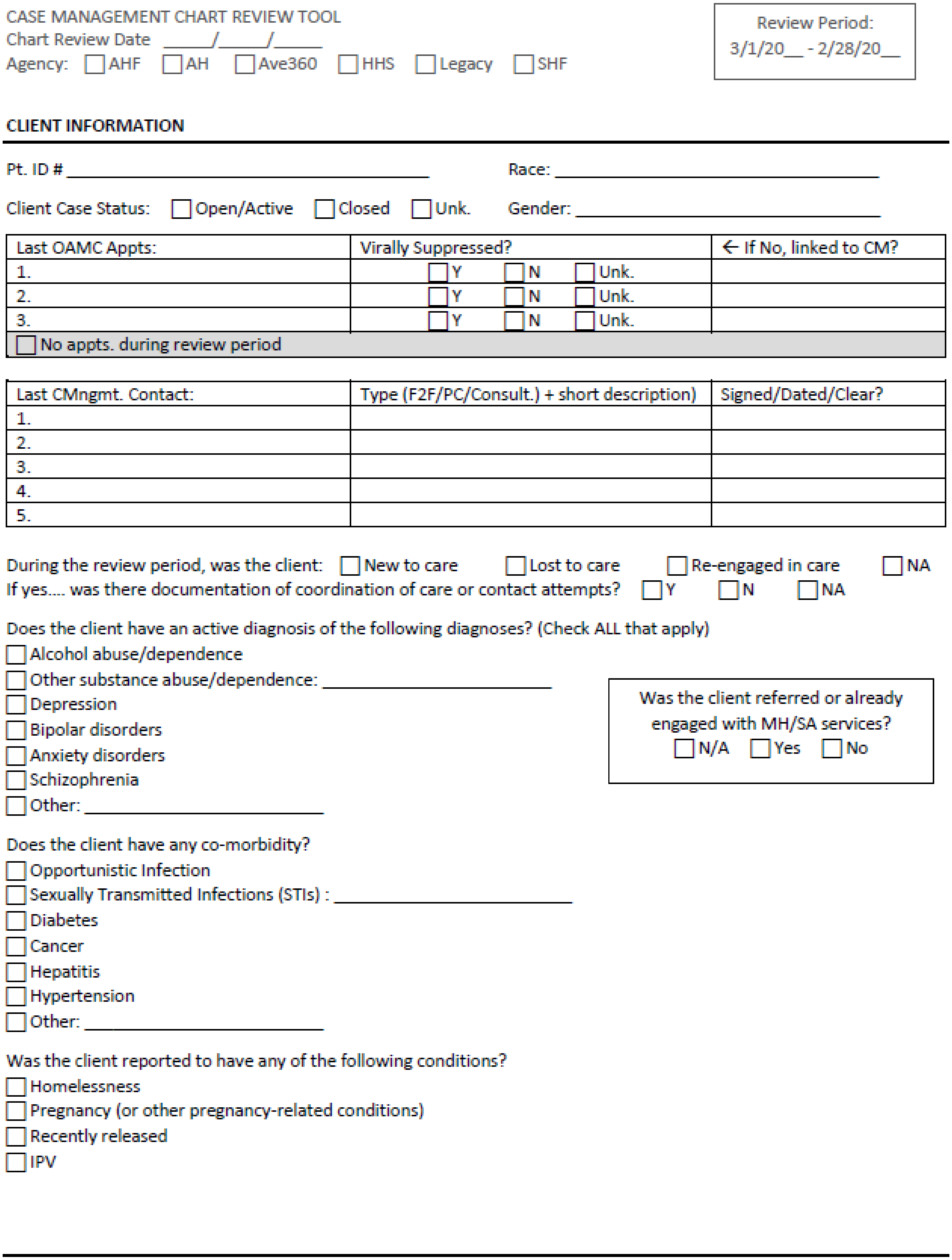
Conclusion

The 2020-2021 Case Management chart review highlighted many trends about the case management client population, strengths in case management performance, and areas identified for future attention and improvement. This report also gives consideration to challenges and barriers related to Covid-19 pandemic.

The most common co-occurring conditions were: Sexually Transmitted Infections (33%), Depression (32%), and Hypertension (25%). Diabetes and Obesity were also relatively common and providing overview information on nutrition counseling may be a useful topic in frontline case management trainings. The prevalence of complex co-morbidities emphasizes the unique benefit that case managers contribute to the HIV treatment setting.

There were also areas of high performance displayed in this chart review. Most (43 %) of the clients in the sample had at least three HIV-related primary care appointments within the review year. Case Management staff demonstrated a high level of coordination of care in areas. For example, 90% of the clients who were New, Lost, or Returning to Care (or some combination) received coordination of care activities from case management to retain them in care.

Appendix (Case Management Chart Review Tool)



CASE MANAGEMENT CHART REVIEW TOOL
Chart Review Date _____/_____/_____
Agency: ☐ AHF ☐ AH ☐ Ave360 ☐ HHS ☐ Legacy ☐ SHF

Review Period:
3/1/20__ - 2/28/20__

CLIENT INFORMATION

Pt. ID # ________________________________ Race: ______________________________

Client Case Status: ☐ Open/Active ☐ Closed ☐ Unk. Gender: ______________________________

Last OAMC Appts:	Virally Suppressed?	← If No, linked to CM?
1.	☐ Y ☐ N ☐ Unk.	
2.	☐ Y ☐ N ☐ Unk.	
3.	☐ Y ☐ N ☐ Unk.	
☐ No appts. during review period		

Last CMngmt. Contact:	Type (F2F/PC/Consult.) + short description)	Signed/Dated/Clear?
1.		
2.		
3.		
4.		
5.		

During the review period, was the client: ☐ New to care ☐ Lost to care ☐ Re-engaged in care ☐ NA
If yes.... was there documentation of coordination of care or contact attempts? ☐ Y ☐ N ☐ NA

Does the client have an active diagnosis of the following diagnoses? (Check ALL that apply)
☐ Alcohol abuse/dependence
☐ Other substance abuse/dependence: ________________________
☐ Depression
☐ Bipolar disorders
☐ Anxiety disorders
☐ Schizophrenia
☐ Other: _________________________

Was the client referred or already engaged with MH/SA services?
☐ N/A ☐ Yes ☐ No

Does the client have any co-morbidity?
☐ Opportunistic Infection
☐ Sexually Transmitted Infections (STIs) : _________________________
☐ Diabetes
☐ Cancer
☐ Hepatitis
☐ Hypertension
☐ Other: _________________________

Was the client reported to have any of the following conditions?
☐ Homelessness
☐ Pregnancy (or other pregnancy-related conditions)
☐ Recently released
☐ IPV

INSURANCE, BENEFITS, AND INCOME INFORMATION

Health Insurance: ☐ Uninsured ☐ Medicaid ______ ☐ Medicare_______ ☐ Commercial __________
☐ VA ☐ Other? ________

Spouse/partner:	Children:	Other Dependents:	TOTAL HOUSEHOLD SIZE 1 2 3 4 5 6 7 8 9 10 Unk
Client Income $:	Spouse Income $:	Other Income $:	TOTAL HOUSEHOLD INCOME $:

Did the client lose insurance or coverage during the review period? ☐ Y N ☐ Unk. ☐
If so, were they provided with information/education or assistance? ☐ Y N ☐ NA ☐

CASE MANAGEMENT SERVICES

What types of services were provided by a **Medical Case Manager** (MCM?)	What types of services were provided by a **Service Linkage Worker** (SLW?)	Was the client referred for **Clinical Case Management** services in the review period?
☐ **NA (Client not assisted by MCM)** ☐ Comprehensive assessment ☐ Service Plan ☐ Medication adherence counseling ☐ Coordination of medical care ☐ Transportation ☐ ADAP/medication assistance ☐ Eligibility ☐ Community resource/benefits brokerage ☐ Other ________________ Did client meet criteria for MCM? Y ☐ N ☐ Unk. ☐	☐ **NA (Client not assisted by SLW)** ☐ Brief assessment ☐ SLW referred client to OAMC ☐ OAMC visit scheduled by SLW ☐ SLW accompanied client to OAMC ☐ SLW called client to remind about OAMC visit ☐ Client did not keep OAMC appt. and SLW contacted them ☐ ADAP/medication assistance ☐ Transportation voucher ☐ Eligibility Were any of the above services provided by an Outreach Worker? Y ☐ N ☐ Unk. ☐	☐ **No- not applicable** ☐ No- applicable, but no referral documented ☐ Yes- and there is evidence of coordination of services ☐ Yes- and there is no evidence of coordination of services ☐ Yes- but client refused services or is already engaged in treatment

Was the case discharged/closed for CM during the review period? Y ☐ N ☐ NA ☐ Unk. ☐
If yes.......
Client met agency criteria for closure? Y ☐ N ☐ NA ☐ Unk. ☐
Client completed treatment program (CCM) Y ☐ N ☐ NA ☐ Unk. ☐
Date and reason noted? Y ☐ N ☐ NA ☐ Unk. ☐
Summary of services received? Y ☐ N ☐ NA ☐ Unk. ☐
Referrals noted? Y ☐ N ☐ NA ☐ Unk. ☐
Instructions given to client at discharge? Y ☐ N ☐ NA ☐ Unk. ☐

ASSESSMENTS & SERVICE PLANS

		If no assessment or plan:		
Brief Assess. Date 1:	Brief Assess. Date 2:	☐ evidence of one just outside of review period	☐ reason documented	☐ enough info to complete
Comp. Assess. Date 1:	Comp. Assess. Date 2:	☐ evidence of one just outside of review period	☐ reason documented	☐ enough info to complete
Service Plan Date 1:	Service Plan Date 2:	☐ evidence of one just outside of review period	☐ reason documented	☐ enough info to complete

COMPLETED ASSESSMENTS

	MOST RECENT ASSESSMENT TYPE (circle one) Comprehensive Brief					NEXT MOST RECENT ASSESSMENT TYPE (circle one) Comprehensive Brief				
Domain	Assessed?	Need Identified?	Accounted for in Service Plan?	Accounted for in progress notes?	Follow-up (referral, action, etc.)	Assessed?	Need Identified?	Accounted for in Service Plan?	Accounted for in progress notes?	Follow-up (referral, action, etc.)
Medical/Clinical										
Vaccination										
Nutrition/Food Pantry										
Dental Care										
Vision Care										
Hearing Care										
Home Care Needs										
Basic Necessities/Life Skills										
Mental Health										
Substance/Alcohol Use										
Abuse History										
Housing/Living Situation										
Support System										
Child Care/Guardianship										
Insurance Benefits										
Transportation										
HIV-Related Legal										
Cultural/Linguistic										
Self-Efficacy										
HIV Education/Prevention										
Family Planning/Safer Sex										
Employment/Income										
General Education/Vocation										
Financial Assistance										
Medication Adherence										
Client Strengths										
Other										

International Journal of Integrated Care

Case Management Programs for Improving Integrated Care for Frequent Users of Healthcare Services: An Implementation Analysis

RESEARCH AND THEORY

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ABSTRACT

Introduction: Case management programs (CMP) for frequent users of healthcare services presenting complex healthcare needs constitute an effective strategy to improve patient experience of integrated care and to decrease healthcare overuse and cost. This study sought to identify characteristics of these programs, and their implementation contexts, that help to improve patient self-management, experience of integrated care, and healthcare services use.

Methods: A mixed methods multiple embedded case study design was conducted, with six CMP implemented in six hospitals of a region of Quebec (Canada).

Results: Within-case analysis describes the structural, environmental, organizational, practitioner, patient, and innovation level characteristics of each CMP and their services integration outcomes based on patient experience, self-management and healthcare services use. Cross-case analysis suggests that the skills, leadership and experience of the case manager, providers' access to the individualized services plan, consideration of the needs of the patient and family members, their participation in decision-making, and the self-management approach, impact integrated care and healthcare services use.

Conclusion and discussion: This study underscores the necessity of an experienced, knowledgeable and well-trained case manager with interpersonal skills to optimize CMP implementation such that patients are more proactive in their care and their outcomes improve.

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KEYWORDS:
implementation analysis; case management program; multiple embedded case study; high users of healthcare services; integrated care

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INTRODUCTION

Individuals with chronic conditions sometimes have complex healthcare needs, due to mental health comorbidities and/or social vulnerabilities [1] and become frequent users of healthcare services [2–4]. Organizing services to improve care for these patients with complex needs is a priority for healthcare systems [4] and requires an integration of clinical services offered by health and social care professionals, as well as community-based ones [5]. Models of integrated care such as case management [6] improve the quality of care, patient satisfaction, access to care, and care transitions [7, 8], and reduce the probability of hospitalization, when compared with usual care [9].

Case management programs (CMP) for frequent users of healthcare services with complex needs constitute an effective strategy to improve patient experience of integrated care and to decrease healthcare overuse and cost [10–12]. Case management is a dynamic, systematic and collaborative approach used to ensure, coordinate, and integrate care and services for a clientele. The case manager is a key practitioner or navigator (often a nurse or a social worker) who evaluates, plans, implements, coordinates, and prioritizes services based on individuals' needs, and offers self-management support in close collaboration with health, social and community partners [13].

A majority of studies have reported the effectiveness of CMP with indicators such as improvement in patient satisfaction and quality of life, and reduction of healthcare services use, ED visits, hospitalization rates, and cost [10–12]. Although the evidence in support of CMP is strong, there remains a paucity of evidence about the implementation process that lead to these outcomes in local contexts [14]. The aim of this study was to identify characteristics of CMP, and the contexts where they are implemented, that help to improve patient self-management, experience of integrated care, and healthcare services use.

METHODOLOGY

DESIGN OF THE STUDY

This was a case study, more specifically a multiple embedded case study with a mixed-methods design [15]. Such a methodology appears the most appropriate for an implementation analysis in a complex system, and to study cases, with varied contexts, as they evolve over time [15, 16]. In addition to allowing for an in-depth analysis of each case, the analysis strategies used in this design help to systematically compare trends observed between cases. It is recommended that four to ten cases be considered [17] in the multiple case study logic of theoretical replication [15]. This study included six cases, where each case was the CMP implemented in each hospital. The three different units of analysis that were interwoven to obtain an in depth understanding of each case were: 1) the hospital (organizational 'macro' level); 2) the CMP itself for frequent users of services ('meso' level) and 3) the individual ('micro' level), more particularly patients who are frequent users.

CONTEXT OF THE STUDY

The study was realized in the Saguenay-Lac-Saint-Jean region of Quebec, a province in Canada. This region is the third largest territory in Quebec and has a very low average population density of 2.9 inhabitants per square kilometre. Much of the population is French-speaking and less than 1% are immigrants. Compared to the whole Quebec population, the residents of the Saguenay-Lac-Saint-Jean region have lower educational attainment and experience more mental health conditions [18]. In the province of Quebec, regions are divided into administrative sectors referred to as County Regional Municipalities (CRM). In the Saguenay subregion, one of these CRM is served by three hospitals, and in the Lac-Saint-Jean subregion, three of these CRM are each served by a hospital.

CASE MANAGEMENT PROGRAM

In 2008, the Saguenay-Lac-Saint-Jean health and social services agency mandated the six hospitals of its territory to implement CMP for frequent users of healthcare services. Between 2009 and 2015, six CMP, the cases included in this study, were deployed by stakeholders' committees made up of a coordinator, managers, services coordinators and case managers. CMP aimed to improve self-management support and integrated care, and decrease ED use, hospitalizations as well as healthcare cost. Case managers (a nurse or a social worker or both in dyad) in each of the six hospitals were recruited and trained to the case management approach. The training enabled the case managers to identify patients with complex care needs, assess their specific needs, and develop the individualized service plans (ISP) to respond to those needs in collaboration with the patient, their relatives and other actors involved in the implementation of the ISP, including nurses, social workers, family physicians, pharmacists, and representatives of community organizations.

In 2015, during the data collection of the study, the government of Quebec reorganized the healthcare system by merging local hospitals into larger regional entities in order to centralize health and social services. This resulted in an effort from a single CMP committee made up of a coordinator, a manager, a performance improvement consultant and case managers to standardize the program offered by the six hospitals. Members of the committee also discussed challenges and facilitators to the implementation of the CMP in this new context, as well as factors at the healthcare system level that could influence the case managers' work. Criteria for enrolment were standardized, targeting patients with more than six ED visits or three hospitalizations in the previous year. Frequent users were identified electronically through hospital admissions and ED records. The provincial healthcare system reorganization had major impacts on clinical, professional, administrative, management and governance aspects of the healthcare system. For example, there was staff turnover at the case manager and manager level, which affected the implantation of CMP in many cases.

CONCEPTUAL FRAMEWORK

Two conceptual frameworks guided this study. First, given that we were interested in the implementation of CMP, we used Chaudoir et al. [19] which proposes five broad categories of factors to consider when evaluating the implementation of an innovation, namely: 1) structural and environmental-level factors; 2) organizational-level factors; 3) practitioner-level factors; 4) patient–level factors, and 5) innovation-level factors. Second, to examine patient experience of integrated care, the model proposed by the National Collaboration in Integrated Care and Support was used [20]. It consists of six dimensions of care integration based on patient experience: 1) consideration of patient and family needs, 2) communication with the patient and between practitioners, 3) access to information, 4) patient involvement in decision-making, 5) care planning, and 6) transitions between various professionals.

PARTICIPANTS

Key informants involved in the six CMP and healthcare services used by patients with complex health needs were recruited through purposeful sampling [21] in each hospital. Patients recruited were frequent users of hospital services, who had six visits to the ED or more, or three hospitalizations or more in the previous year.

DATA COLLECTION

An implementation analysis strategy [22] guided the three methods of qualitative data collection and the method of quantitative data collection. While qualitative methods were used to inform self-management and patient experience of integrated care, quantitative data collection methods allowed the measurement of ED services use.

Qualitative data

Individual interviews and focus groups

Semi-structured individual interviews (n = 56) and focus groups (n = 11) were conducted between December 2014 and May 2018 with 24 patients, 12 case managers and intermediate managers, 8 senior managers, 12 family physicians, 25 community stakeholders and 6 pharmacists, with interview guides, adapted for each type of actor, and addressed the five main categories of factors of the Chaudoir et al. framework of innovation implementation [19], and the six dimensions of patient experience [20]. Data saturation was not the goal for each group, but the diversity of actors engaged provided a complete representation of each case [23]. All individual interviews and focus groups were audio recorded and transcribed verbatim.

Participant observation

A member of the research team performed participant observation during one case management training session, individual case manager activities (n = 6) (e.g. evaluation of targeted patient needs, contacts with patients and their healthcare providers, ISP meetings), and quarterly meetings of the CMP committee of each of the six hospitals (n = 11). The member of the research team was invited to attend all committee meetings and share updates about the research project. These meetings were also an opportunity to consult committee members on how the research project could provide new knowledge that would help them. Data were collected using field notes [21].

Document analysis

Minutes of the CMP committee meetings were collected as they provided insight into the characteristics of the CMP and the CMP implementation, including challenges and means to overcome them [24].

Quantitative data

Clinical and administrative data

Using the hospitals' Magic Chronique computer software [25], the number of frequent users of ED was recorded monthly for each hospital beginning in December 2012 (the year preceding the start date of the study) and ending on May 2018. Data quality was controlled using an integrated model of information quality and a series of validation algorithms.

ANALYSIS

Qualitative data

For each case, all qualitative data were analysed together as one data corpus using a deductive (themes based on the conceptual frameworks [19, 20] and inductive (themes emerging from the data) thematic analysis [26]. All data sources were examined to identify characteristics of CMP, and their contexts that can be related (positively or negatively) to the examined outcomes, i.e. patient self-management, experience of integrated care, and healthcare services use. Qualitative data were managed by two authors who used NVivo V.11 server software (QSR International Pty). Other authors, including an experienced patient partner, participated in the analysis. Persistent observation, and methodological and investigator triangulation were used to ensure credibility [27].

Quantitative data

The number of ED frequent users (six visits or more in the previous year) was tabulated for each hospital and represented in one graph to allow for visual comparison.

Integration of qualitative and quantitative data

Qualitative and quantitative results were compared for each case [28]. Qualitative data was analysed first, quantitative data second, then cross-analyses merged the two corpora of data [15]. A case history was written for each case (*Table 2*) to summarize merged data [26]. To compare the six case records, three analytic techniques used in case study research were used, namely pattern comparison, search for competing explanations and construction of explanations [15]. Management, data reduction and cross case comparisons were conducted with NVivo V.11 software using matrix queries.

The study was approved by the ethics committee of the Centre for integrated health and social services of Saguenay-Lac-Saint-Jean (2014–015).

RESULTS

Table 1 provides the descriptive characteristics of each of the six CMP.

Figure 1 illustrates the evolution of the number of ED frequent users during the implementation of the CMP. While the number of frequent users increased considerably in the case A and increased slightly in the case D, an important decrease was observed for the case C and a slight decrease in the case F. These last two cases are considered "success stories". The cases B and E remain relatively stable.

INTRA-CASE RESULTS

Table 2 merged qualitative and quantitative data to present case stories.

CROSS-CASE RESULTS

Tables 3 to *5* present the cross-case results. The outcomes (see the legend) are identified according to the five categories of Chaudoir et al. framework.

Legend for *Tables 3, 4* and *5*

Outcomes associated with each CMP characteristic

- **1** Integrated care
  - **1.1** Consideration of patient and family needs
  - **1.2** Communication with the patient and between practitioners
  - **1.3** Access to information
  - **1.4** Patient involvement in decision-making
  - **1.5** Care planning
  - **1.6** Transitions between various health professionals and practitioners
- **2** Self-management
- **3** Health services use

CHARACTERISTIC	CASE					
	A	B	C	D	E	F
Population of hospital service zone in 2017 (n)	78 824	67 264	22 554	52 855	25 615	31 500
Area of the hospital service zone (km^2) [29]						
CRM	1 126			2 781	36 770	17 799
City-center	156	216	262	196	296	153
Population density (resident/km^2)						
CRM	0.6			18.6	0.7	1.8
Main city	384.4	253.9	75.9	237.2	50.3	71.3
Year of CMP creation	2009	2012	2013	2012	2015	2013
Case manager	Nurse-social worker dyad	Social worker	Nurse	First: nurse-social worker dyad Later: only a nurse	Social worker	First: nurse-social worker dyad Later: only a nurse
ISP access modality for healthcare providers (other than case manager)	No access	Hard copy folder (n = 1) in the ED	Hard copy (n = 1) in the ED	Digital folders (n = 3)	Digital (n = 1) folder in the ED	Digital (n = 1) and hard copy (n = 1) folders in the ED

Table 1 Characteristics of the six case management programs.

CMP: case management program; CRM: County regional municipality; ED: Emergency department; ISP: Individual service plan.

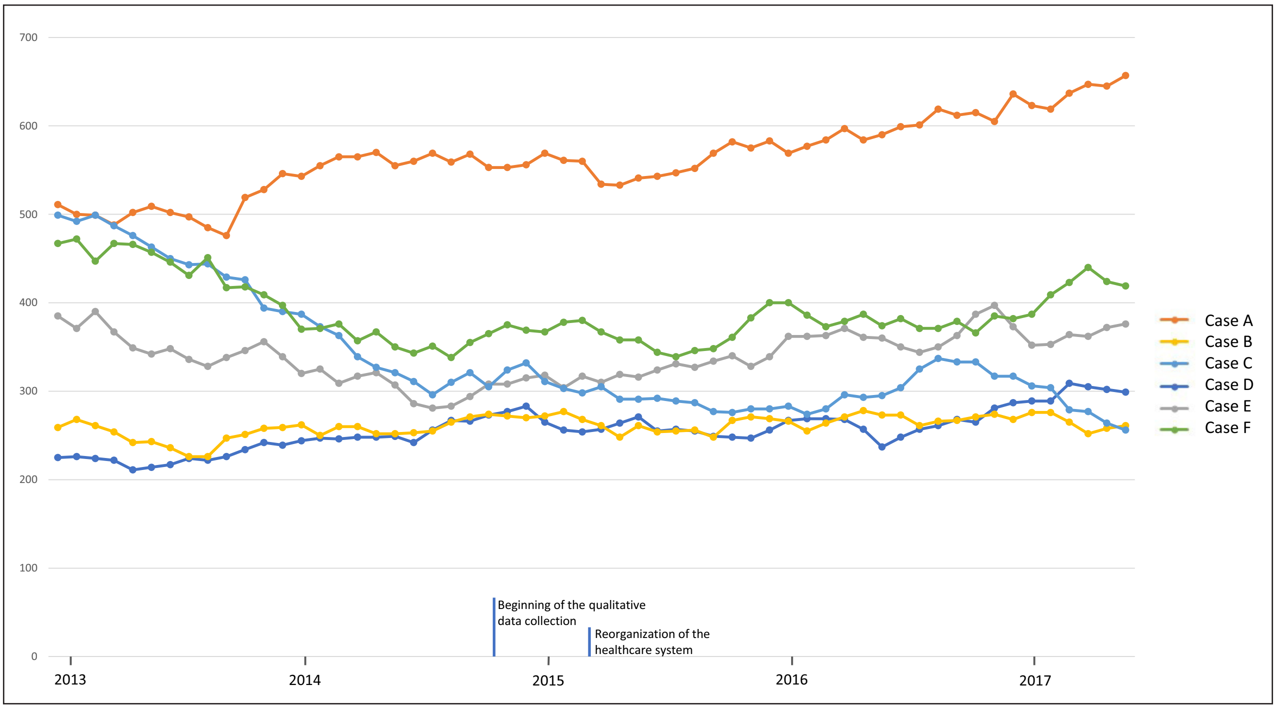

Figure 1 Number of ED frequent users* for each hospital.

* FU: 6 ED visits or more in the previous year.

CASE	DESCRIPTION
A	Located in the largest urban centre of the region, this CMP began as a committee of health and social care providers, from various hospital departments, and dedicated to the case management approach with their respective clientele. Then, an official CMP was launched to serve a larger volume of patients. It was led by a nurse-social worker dyad who identified frequent ED users in real-time, thereby ensuring timely patient management. Due to the considerable number of health and social services organizations and providers in this area, interpersonal connections and knowledge between the local actors were difficult to achieve. The care was thus siloed rather than integrated and coordinated. The reorganization of the Quebec healthcare system in 2015 had major impacts on health and social services in general, and on the CMP in particular, including staff turnover at the intermediate and senior management levels and a general climate of insecurity regarding the program sustainability. Due to the reorganization and despite the senior manager's wish to maintain all CMP activities, the CMP was stopped in November 2015. In May 2018 (the end of the qualitative data collection phase), it had still not been rebooted. The quantitative data indicate a decrease of ED frequent users at the beginning of the program, while a continuous increase in the number of ED frequent users began when the CMP stopped.
B	Based in the second largest urban hospital in the region, the CMP served a population with a high prevalence of mental health disorders and social problems. The case manager was a social worker who was not only responsible for coordinating patient care, but who also worked with patients to reduce their high use of care services. Over the course of this study, there was a high turnover of case managers and this seemed to influence the engagement and openness of patients and providers towards the CMP. Moreover, changing leadership among the case managers resulted in mixed program effects over the years. The reorganization of the healthcare system generated staff turnover and shortage as well as lack of other resources (e.g. physical place to work). Consequently, providers were dissatisfied with the CMP implementation and, ultimately, became reluctant to accept any new initiative from senior managers or health authorities, including the CMP. However, with the support of senior managers, the CMP was maintained. The number of ED frequent users remained stable over the study duration.
C	The CMP was in a small rural area close to an urban centre; thus, benefiting from geographic proximity between patients and providers. Given that the case manager worked near the family physicians in the clinics, information circulated fluidly, and patient follow up was rapid. Many patients of this CMP were elderly or had chronic pulmonary disease. The case manager was an experienced nurse who was well known by patients and providers before the CMP implementation because this person had been working in the area for many years. Moreover, since becoming the case manager of this CMP in 2013 when it began, this person had worked hard to make herself even more known among the CMP stakeholders and to build relationships with providers. Given these relationships of trust, the initial resistance to the CMP was reduced. Additionally, because the case manager met with patients and ED personnel frequently, follow up was more rapid and efficient. Finally, due to the strong support from senior manager, the case manager had a lot of autonomy, and was thus able to adapt to the needs of patients and providers. Over the course of the case study, the CMP did not change very much. In fact, the potential negative effects of the reorganization of the Quebec healthcare system on the CMP were mitigated by the stability of the case manager and the management team. The number of ED frequent users decreased steadily during the study period.

(Contd.)

CASE	DESCRIPTION
D	The hospital deploying this CMP serves a small territory facilitating inter-professional and inter-organizational collaboration, particularly between family physicians and the case manager. At the beginning of the program in 2012, an emergency nurse identified frequent users who were referred to family physicians. Three years later, in 2015, a part-time case manager was hired, but in a nearby clinic, not in the hospital. To improve coordination, two teams, each composed of a part-time dedicated nurse, a nursing assistant and a family assistant were created in two neighbouring localities near the hospital. However, the lack of support and unclear guidance from managers, and the demobilization of health and social providers due to the reorganization of healthcare system in 2015, led to the replacement of these teams by the part-time case manager from another area, which had to coordinate a much larger territory (see case F). Despite the many challenges this case manager faced (e.g. remote coordination, lack of time, creation of links with managers and health and social providers), and due to her expertise, this person was able effectively lead the CMP. The number of ED frequent users remained fairly stable over the study duration.
E	Liaison nurses assigned to this CMP included organizations that had pre-existing partnerships and a strong potential for collaboration in CMP, namely the hospital's ED and mental health department, and the service area's family medicine groups and local community health centre. In March 2015, just after its implementation, the CMP was interrupted due to the reorganization of the health and social services system. Thanks to the initiative of senior and intermediate managers, the CMP activities were temporarily resumed at the end of 2016, but stopped for a second time in the summer of 2017 due to persistent management and clinical staff's instability. Given this short time frame (six months), the new nurse case manager was unable to create and consolidate collaboration among all CMP organizations. In March 2018, a new part-time social worker case manager was assigned to the CMP. In December 2018 (about the end of the qualitative data collection period), this case manager had still not received a training. The number of ED frequent users remained fairly stable for the duration of this study.
F	The CMP began in 2013, initially with a dyad composed of a nurse and a social worker. During the first year, human resources turnover in the hospital resulted in program interruptions. Following the reorganization of healthcare services in 2015, only the nurse stayed part-time as the case manager and focussed for the most part on elderly patients. The geographic proximity and leadership of this person helped to nurture partnerships with ED social workers, physicians and family medicine groups. For example, the case manager established a formal referral structure that linked family physicians, nurses, patients, and himself. By the end of the data collection, the case manager had finally been assigned full time to implement and execute the CMP in cases D, E and F. There were now enough human resources to deploy the CMP and consolidate existing partnerships. The number of ED frequent users decreased over the study period.

Table 2 Case management program (CMP) implementation in each setting: case stories.

In the tables, the arrows represent an increase (↑), a decrease (↓), or an effect on another outcome (→), while the + and – signs represent contextual factors having a positive or negative impact on the implantation of CMPs.

CROSS-CASE SYNTHESIS

The skills, leadership and experience of the case manager seem to be the characteristics of the CMP that have the most positive influence on patient experience of integrated care, self-management and healthcare services use. The case manager's leadership was critical in both successful cases (C and F), i.e. where we observed a decrease of ED visits. Their coordination, communication and networking skills improved integrated care by facilitating collaboration among professionals and also the transitions between health services, for which information access was a key. These improvements were also observed when the case manager was experienced, well-known in his/her workplace (C and F) and located near the providers (cases D, E, F).

Regarding the other characteristics of the CMP, four stand out from our cross-case analysis: 1) the individualized services plan (all cases), 2) patient and family needs assessment (all cases), 3) patient and family participation in decision-making (all cases), and 4) the self-management approach (cases C, D and F).

Our results suggest that where staff turnover and thus, health care team instability, was present due to organizational issues and the health system reorganization (cases B, D and E), negative impacts on care integration, especially regarding communication and care transitions, were observed. However, when case managers were well supported by their managers (cases B, E and F), they had the opportunity to create more personalized care trajectories. Therefore, patient transition through care pathways was optimized and their use of services was more appropriate. Reassurance of patients by their case manager appears to be particularly important for those with anxiety as it seems to have contributed to a reduction in their ED visits.

DISCUSSION

This study underscores the necessity of an experienced, knowledgeable, and well-trained case manager with strong interpersonal skills to optimize CMP implementation such that patients are more proactive in their care and their outcomes improve. These qualities improve care coordination which is one of the main components of CMP [30, 31]. Similarly, Ross et al. pointed out that the case manager skills such as ability to develop good interpersonal relationships, problem-solving, negotiation and brokerage, prescribing qualifications play a key role to facilitate CMP implementation and improve outcomes [32]. Case manager training could include a focus on these skills. Indeed, a qualitative systematic review by Joo et al. revealed that insufficient training was a barrier

CATEGORIES EMERGING CHARACTERISTICS	OUTCOMES					
	CASE A	CASE B	CASE C	CASE D	CASE E	CASE F
Structural and environmental-level factor						
(+) Proximity between providers		↑ patient support (1.1)		↑ communications between healthcare professionals (1.2) ↑ healthcare transition (1.6)	↑ communications between healthcare professionals (1.2) ↑ healthcare transition (smaller ↑ for remote services) (1.6)	↑ collaboration with medical teams leading to ↑ comprehensive care and ↑ understanding of patient needs (1.1) ↑ communication between case manager, managers and healthcare professionals (1.2)
Organizational-level factor						
(–) Staff turnover and healthcare teams' instability		↓ continuity of care (1.6)		↓ case manager follow-up with healthcare professionals (1.2)	↓ continuity of care and ↑ repetition of patient medical history (1.6)	↓ consistency of patient support (1.1) ↓ patient information (1.2) ↓ continuity of care (1.6)
(+/–) Information access/No information access			↑ response to patient needs (1.1) ↓ inadequate use of healthcare services given emergency nurses' access to ISP* (3)	↓ assessment of patient situation (1.3) ↓ continuity of care between hospital and clinics (1.6) ↓ continuity of care when ISP not accessible to all healthcare professionals (1.6)	↑ response to patient needs (1.1) ↑ communication between case manager, ED physicians, and liaison and mental health nurses (1.2)	↑ health care transitions (1.6)
(+) Manager support		↑ service access for patients with most complex needs (1.1) ↑ service trajectories (1.6) ↓ use of health and social care services (3)				↑ case manager legitimacy and autonomy → new trajectories of care and ↑ continuity of care (1.6) ↓ use of healthcare services (3)

Table 3 Structural, environmental, and organizational characteristics influencing integrated care, self-management and health services use for each case.

ISP: Individualized services plan.

CATEGORIES EMERGING CHARACTERISTICS	OUTCOMES					
	CASE A	CASE B	CASE C	CASE D	CASE E	CASE F
Practitioner-level factor						
(+) Case manager leadership (skills, attitudes and personal qualities, previous experience, networking)		↑ access to other healthcare providers; leads to better follow-up and ↓ healthcare use (3)		↑ patient-centred care and ↑ access to adapted services (1.1) ↑ continuity of care (1.6) ↓ ED visits (because new CTs (3)		
(+) Provider engagement					↑ collaboration, communication and exchange of patient's information between local community health centre and the hospital (1.2)	
(+) Inter-professional collaboration	↑ follow-up and a ↑ response to patient needs (1.1)		↑ sharing and discussion on patient information (1.2) ↓ healthcare use (3)		↑ access to clear and concise patient information (1.3) ↑ continuity of care and care planning (1.5, 1.6) ↑ consultations with other healthcare professional (patient doesn't need to repeatedly see doctor for referrals) (3)	↑ knowledge of patient's overall situation (1.1) ↑ communication between healthcare professionals (1.2) ↑ patient knowledge of care plan (1.3) ↓ patient repeating their medical history (1.6) ↑ patient appropriate use of resources (3)
Patient-level factor						
(+) Anxious patient	↑ patient confidence (given reassurance from case manager) (2) ↓ ED visits (3)					
(+) Patient with self-management skills		↑ patient proactivity in their health and healthy lifestyle choices (2) ↓ ED visits (3)		↑ patient proactivity in their care and healthy lifestyle choices (2) ↓ ED visits (3)		

Table 4 Practitioner and patient characteristics influencing integrated care, self-management and health services use for each case.

CT: care trajectory; ED: emergency department.

CATEGORIES EMERGING CHARACTERISTICS	OUTCOMES					
	CASE A	CASE B	CASE C	CASE D	CASE E	CASE F
Innovation-level factor						
(+) Individualized service plan (ISP)	↑ patient support and follow-up (1.1) ↑ patient involvement in their care (1.4) ↑ access to care (1.6)	↑ care planning (1.5)	↑ inter-professional communication (1.2)	↑ inter-professional collaboration, proximity and knowledge among healthcare professionals, which ↑ communication (1.2), information sharing and discussion (1.3) and healthcare transitions (1.6)	↑ healthcare professionals' knowledge of the ISP (1.3)	
(+) Consideration of patient and family needs		↑ patient adherence to the program (1.1) ↓ healthcare use (3)		↑ case manager's information access (1.3) ↑ patient participation in shared decision-making (1.4)	↑ patient-provider relationship of trust, thus ↑ response to patient needs (1.1) and self-management support (2)	↑ patient's involvement in shared decision-making (1.4)
(+) Self-management support approach			↑ patient confidence, which leads to decreases their health services use (3)			↑ case manager and patient relationship of trust, thus ↑ communication (1.2)
(+/–) Relatives' participation in decision-making/relatives support	↑ knowledge of patient needs and situation, thus ↑ patient follow-up (1.1) ↑ bidirectional information sharing (1.2, 1.3)		↑ knowledge of patient needs and situation (1.1) ↑ patient and relatives' awareness of the care plan (1.3)		↑ patient adherence to ISP (1.5) ↓ hospitalization when relatives take patient to ED (3)	↑ response to patient needs (if very complex needs) (1.1) ↓ services use (3) ↑ use of care plan (1.5) by patients with low literacy (due to self-management support) (2)
(+/–) Case manager access to information			↑ relevance of response to patient needs (1.1) ↑ ISP efficiency (1.5)		↑ inter-professional communication (1.2)	↑ continuity of care (1.6)

Table 5 Characteristics of the innovation (the CMP) influencing integrated care, self-management and health services use for each case.

ISP: Individualized services plan.

to the case manager's role [33]. Likewise, our results also underscored the importance of adequate training, but also that it can be challenging to ensure such training when there is a high turnover of case managers. Hong et al. provide a potential solution to this by suggesting that all care team members receive training, in order to build a relationship of trust with the patient [31].

To improve integrated care, although coordination by a skilled case manager is the core of case management, self-management support is important for CMP as a whole [14, 34, 35]. Self-management support seeks to improve patients' knowledge and awareness of their care plan, self-efficacy, sense of control over their condition, and motivation to take more responsibility for their health [36, 37]. To effectively provide this support, case managers should adopt an approach that is relevant, meaningful and centred on patient needs [32]. When the patient and caregiver manage the patient's care adequately, their use of healthcare services is more appropriate and reduced rates of readmission are observed [38]. Furthermore, encouraging patients and their families to participate in decisions regarding the ISP better meets patient needs, promotes patient and family involvement in patient care and leads to fewer ED visits [35, 39, 40].

It could be argued that in-depth descriptions of the six CMP settings studied would be helpful to judge whether the results of this study are transferable to similar healthcare system settings [41]. However, given that the six CMP are heterogenous in terms of the populations they serve, their urban and rural environments, their size, the types of providers, among other key features (see ***Table 1***), this aspect increases the theoretical transferability of the results. That said, this study's findings should be considered in light of some limitations that could be addressed in future research. First, only one source of quantitative data (ED visits) was used to measure CMP efficacy. Second, the qualitative data did not provide much insight into the factors linked to the 'patient' category of outcomes outlined in the Chaudoir et al. conceptual framework. Third, the qualitative results are relevant to many contextual factors in the other five categories of outcomes, but only those regarding the outcomes of interest (i.e., patient experience of integrated care and integrated care) are reported. Fourth, the case managers' activities were not measured and evaluated. To further increase the credibility of the results, survey studies could be conducted with validated questionnaires that assess the impact of CMP on patients and the results could be triangulated with those presented herein. Finally, exploring system or organization level outcomes could complete the picture of the impact of CMP on frequent users' health outcomes.

Studying CMP as they unfold is crucial to building the knowledge base regarding the components of CMP and the roll-out required to improve integrated care. This study is one of few that explore the implementation of CMP for frequent users of ED services in hospital settings. Additional implementation studies conducted in differing contexts or healthcare systems would be useful to confirm and further enrich the findings. In this regard, Malebranche et al. recently suggested that further research was needed to better understand the advantages and disadvantages of implementing case management as primary care program versus predominantly ED or hospital-based one [42]. Teper et al.'s systematic review of CMP implementation in primary care settings identified common facilitators and barriers of CMP implementation in hospital settings including case managers' skills, training, and relationship building and team communication practices [43]. In a systematic mixed studies review on the barriers of CMP implementation for people with dementia in community-based primary health care, Khanassov et al. also reported the importance of communication between case managers and other professionals and services [44]. Identifying contextual barriers to CMP implementation can help to select more effective implementation strategies resulting in increased positive outcomes [44, 45].

Based on the results of the study, recommendations can be made to senior and intermediate managers and clinicians for the planning and implementation of CMP. Senior managers should ensure ongoing support for the implementation of CMP and information sharing among health professionals. They should ensure stability in the health and social care teams, especially to maintain an experienced case manager. They also have a responsibility to promote the culture of a person-centred approach, i.e. one that encourages the consideration of patients' needs and shared decision-making. Intermediate managers should facilitate the skills, leadership and experience of the case manager, as well as his/her proximity to providers. They will need to focus on the case manager's skills during the hiring process and provide quality training in case management with frequent users. In addition, intermediate managers should foster professional development by, for example, allowing time for the case manager to participate in a community of practice or co-development activities. Clinicians must consider the needs of patients and their families when implementing the CMP. They should also provide support to patients and encourage their autonomy and involve them and their families in decision-making.

CONCLUSION

This study underscores the necessity of an experienced, knowledgeable and well-trained case manager with interpersonal skills to optimize CMP implementation such that patients are more proactive in their care and their outcomes improve. Providers' access to the individualized services plan, consideration of the needs of the patient and family members, their participation in decision-making, and the self-management approach, also impact patient experience of integrated care, self-management and services use.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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RESEARCH ARTICLE

Case management programs for people with complex needs: Towards better engagement of community pharmacies and community-based organisations

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Abstract

Introduction

The objectives of this study were 1) to describe how case management programs engaged community pharmacies and community-based organisations in a perspective of integrated care for people with complex needs, and 2) to identify enablers, barriers and potential strategies for this engagement.

Methods

Using a descriptive qualitative design, individual interviews and focus groups with patients, healthcare providers and managers were analysed according to a mixed thematic analysis based on a deductive (Rainbow Model of Integrated Care) and an inductive approach.

Results and discussion

Participants highlighted the individualized service plan as a significant tool to foster a shared person-focused vision of care, information exchanges and concerted efforts. Openness to collaboration was also considered as an enabler for community stakeholders' engagement. The lack of recognition of community-based organisations by certain providers and the time required to participate in individualized service plans were outlined as barriers to professional integration. Limited opportunities for community stakeholders to be involved in decision-making within case management programs were reported as another constraint to their engagement. Cultural differences between organisations regarding the focus of the intervention (psychosocial vs healthcare needs) and differences in bureaucratic structures and funding mechanisms may negatively affect community stakeholders' engagement. Formal consultation mechanisms and improvement of communication channels between

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cannot provide the entirety of the dataset of this study. The consent form based on this framework and signed by the participants contains a section in which they have agreed that their data may be reused, but only as part of a sub-study that must be reviewed and approved by the responsible ethics committee. Researchers who wish to access the data can request it at the following contact information: Comité d'éthique de la recherche / Research Ethic Board Centre intégré universitaire de santé et de services sociaux du Saguenay–Lac-Saint-Jean E-mail: guichetunique.slsj@ssss.gouv.qc.ca Project #2014-015.

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healthcare providers and community stakeholders were suggested as ways to overcome these barriers.

Conclusion

Efforts to improve care integration in case management programs should be directed toward the recognition of community stakeholders as co-producers of care and co-builders of social policies across the entire care continuum for people with complex needs.

Introduction

People with complex care needs are characterized by multiple chronic diseases, mental health comorbidities and/or social vulnerabilities [1]. These individuals are at greater risk for adverse health outcomes, reduced quality of life and increased mortality [2, 3]. They constitute a small heterogeneous group (10% of all users) that generates disproportional costs (70%) for the health system in Canada as in many industrialized countries [4, 5]. Their high use of emergency department services and hospitalizations [5–7] is generally due to fragmented and episodic care between healthcare services [8, 9]. As a result, providing appropriate services that meet the needs of this population is required and can be achieved through integrated care. Integrated care is "the search to connect the healthcare system (acute, primary medical, and skilled) with other human service systems (e.g. long-term care, education, and vocational and housing services) in order to improve outcomes (clinical, satisfaction, and efficiency)" [10]. Case management programs (CMPs) are increasingly used to improve the integration of services [11, 12]. Defined as 'collaborative, client-driven processes for the provision of quality health and support services through the effective and efficient use of resources' [13], their benefits for patients include the improvement of self-management skills, adherence, satisfaction, health status and quality of life. CMPs also benefit the healthcare system by improving the quality of care and reducing healthcare use and cost [14–18].

In Quebec (Canada), community-based organisations (CBOs) and community pharmacies are primary care services linked by formal and informal arrangements to healthcare organisations [19].

CBOs are non-profit organisations that work for social development in their communities [20]. and may include volunteer associations, cooperatives and social economy enterprises whose funding comes from various sources (federal and provincial governments, foundations, donations, social economy, etc.) [21]. Their missions focus on social development, advocacy, housing, and recreation. The populations that they target may include youth, families, indigenous groups, LGBTQ+, people with poor mental health or disabilities, refugees, homeless individuals and immigrants. Their intervention approaches are diverse and include health promotion, informal intervention, outreach work, harm reduction, empowerment, group therapy, and person-focused approaches. As local and collective initiatives, the majority of CBOs focus on community needs, with governance that is based on autonomous and democratic principles, usually involving a board of directors mandated by an assembly of representatives who supervises employee activities and the organisation's strategic orientation [22].

Community pharmacies are private organisations committed to maintaining the overall health of their patients through a variety of interventions: medical information review and treatment follow-up, preparation of medication, adjustment and initiation of treatment, and daily consultations with people who have questions [23]. Community pharmacists are indispensable partners for patients with polypharmacy [24, 25]. They educate and advise people on the use of over-the-counter or prescribed medication and natural health products; support people seeking solutions to minor health problems; contribute to patients' education regarding healthy lifestyles; and if necessary, refer patients to other health and social services [23].

Research has demonstrated the need for and benefits of engaging CBOs and community pharmacies in hospitals or primary care programs, such as CMPs, for people with complex care needs [26–28]. These community stakeholders, who are deeply rooted in their communities, can facilitate a close connection with people who live in the surrounding area [29]. As such, they can contribute significantly to identifying people with complex care needs [27] and to supporting them as they navigate the health system [30]. Furthermore, most CBOs offer person-focused interventions that target behavioural issues or functional difficulties (e.g. harm reduction, education on healthy lifestyle), which may be an effective component of CMPs, especially if linked to healthcare delivery [30]. Fig 1 illustrates the relationships between the stakeholders engaged in these programs for patients with complex needs.

Despite this evidence, the collaboration between providers from the healthcare system and community stakeholders remains poor due to healthcare professionals' lack of knowledge about CBOs and community pharmacies [31], resulting in low CMP referral rates, complexity of managing multi-organisational initiatives, variable adherence to the programs [26] and poor care transition leadership [30]. Disparities in financial resources, organisational expertise and knowledge, lack of proximity between organisations, differences in the vision of collaboration, and complexity of managing communication and information flow across organisations are other issues that can challenge alliances [32].

It is now recognized that CMPs can help bridge the gap between institutional and community care, and that inter-organisational collaboration, as proposed by these programs, could help "service organisations to shift from traditional 'silo' models of service delivery to increased community-based collaboration and service coordination" [33]. Yet, evidence regarding integrated care in the context of CMPs from stakeholders' perspective remains limited [28, 33–35]. The objectives of this study are: 1) to describe how CMPs engaged community pharmacies and CBOs in a perspective of integrated care for people with complex needs, and 2) to identify engagement enablers, barriers, and potential strategies to overcome these barriers.

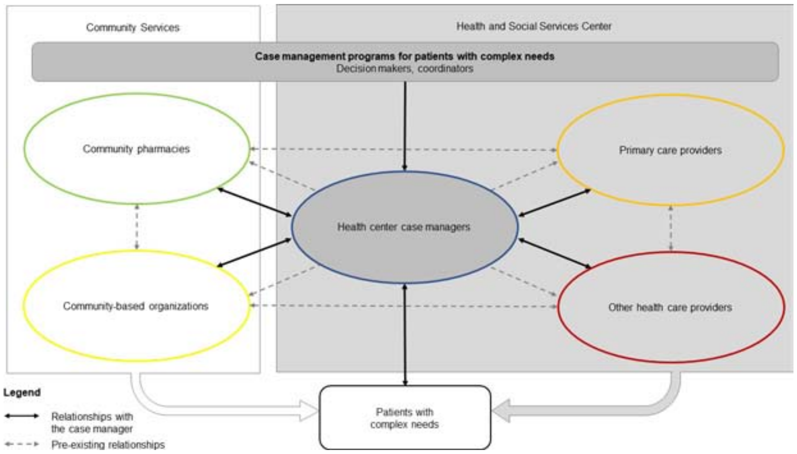

Fig 1. Relationships between stakeholders engaged in CMPs.

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Conceptual framework

The Taxonomy for Integrated Care [36] based on the theoretical foundations of the Rainbow Model of Integrated Care [37] was used in this study. The Rainbow Model of Integrated Care plays interconnected roles at the macro (system integration), meso (organisational and professional integration), and micro (clinical integration) levels, as well as between these levels (functional and normative integration). It was developed from electronic database searches, hand searches of reference lists (snowball method) and by contacting researchers in the field [37]. Thereafter, a literature review and thematic analysis procedure were conducted to refine the model into the taxonomy of fifty-nine key features that helps to profile integrated care initiatives [36]. By developing an international consensus-based taxonomy based on Delphi studies [38] and including every level and stakeholders' perspectives of integrated care, Valentijn et al.'s research has become a reference in the field of integrated care.

At the macro level, system integration refers to the alignment of rules and policies within a system to ensure the provision of continuous, comprehensive, and coordinated services across the entire care continuum [37]. At the meso level, organisational and professional integrations refer to the extent to which organisations and healthcare providers respectively coordinate services across organisations and disciplines. These types of integration processes are especially relevant "in socially disadvantaged populations, such as those with large variations in wealth, education, culture and access to healthcare" [39]. At the micro level, clinical integration is related to how care services are coordinated, share a single process for person-focused coordination of care across time, places and disciplines, and reflect a bio-psychosocial perspective of health. This person-focused coordination taking into account the broader health context is particularly relevant for people with complex healthcare needs that span a large number of service areas [37]. Clinical integration also encompasses the important aspect of the patient as a co-creator in the care process and shared responsibility between the provider and the person [40].

Functional and normative integration are cross-cutting types of integrated care processes linking macro, meso, and micro levels [37]. Functional integration links financial, management and information systems around the primary process of service delivery across clinical, professional, organisational and system integration. Normative integration implies the development and maintenance of a common frame of reference (i.e. shared mission, vision, values and culture) between organisations, professional groups and individuals.

Material and methods

Design

A descriptive qualitative design [41] was used. This approach helps to provide a full description of the individuals' experience, perceptions, and knowledge of the CMPs, in plain language while remaining close to the data and minimizing researcher influence on data interpretation [42, 43]. It helped to obtain a better understanding of the stakeholders' engagement (strategies, barriers and facilitators) in a perspective of integrated care.

Settings

This study was developed as part of the developmental evaluation of a CMP in the Integrated University Health and Social Services Centre (hereafter called 'hospital network") located in the Saguenay-Lac-Saint-Jean region of the province of Québec (Canada) [12]. This hospital network is composed of six health and social services centres (hereafter called 'hospital'), each including a hospital, community and long-term care centres, a child and youth protection centre, and a rehabilitation centre to ensure access, continuity, coordination and the quality of services intended for the population of their local territories [44]. Patients eligible for the CMP had complex needs and had made six or more visits to the emergency department, or had three or more hospitalizations in the previous year. The study was conducted in partnership with hospital network decision makers and a variety of stakeholders [12].

Between 2008 and 2015, the CMP for patients with complex care needs was deployed in all of the hospitals within the hospital network. The program comprised four main components: 1) evaluation of patient needs and goals; 2) development of a patient-centred individualized service plan [45]; 3) care coordination among all partners; and 4) education and self-management support for patients and families [12]. The individualized service plan was planned by the case manager after obtaining the patient's consent. It involved all stakeholders in a meeting, including the patient, primary care providers, secondary and tertiary care providers, community pharmacists, CBO representatives (typically social workers) and the case manager, to detail the patient's needs (including an orientation regarding the action plan for each need) and person-focused shared objectives as well as the services allocated in response to these needs and objectives [45]. The case manager was mandated to validate, share and ensure the follow-up of the individualized service plan with the concerned stakeholders. The aim of the case manager's intervention was to improve quality of life and self-management for patients, and for organisations, it aimed to improve care integration and support for healthcare teams to reduce inappropriate use of services and costs [12].

Data collection and characteristics of participants

Key informants involved in the CMPs were recruited through purposeful sampling [46] in the six hospitals between December 2014 and May 2018. Patients recruited for the study met the program's eligibility criteria, i.e. frequent users of hospital services who had six or more visits to the emergency department, or three or more hospitalizations in the previous year. Patients were approached by their case manager to participate in the study. Those who verbally consented to participate were referred by their case manager to the research team. The research team members then contacted the patients by phone to make an appointment for an individual interview. The researchers' knowledge of the hospital network's organization helped them identify managers, clinicians and community pharmacists. CBO representatives were identified with the help of case managers [46]. Research assistants explained the research project to them as part of the first contact by phone or email. An appointment was then made for the individual interview or focus group.

Individual interviews and focus groups were both used as qualitative data collection methods to promote participation and facilitate exchanges. Individual interviews aim to thoroughly explore each participant's views, experiences, beliefs, and knowledge, while focus groups use group dynamics to highlight the variation of viewpoints held in the targeted population [47]. Focus groups were used as an alternative method to individual interviews, gathering selected types of actors to facilitate their participation, before or after one of their scheduled meetings. One-hour individual interviews (n = 58 participants) were conducted with people with complex care needs (n = 25), managers, case managers and coordinators (n = 13), family physicians (n = 16), and community pharmacists (n = 4). Focus groups (n = 13, including 71 participants) lasting between 45 and 90 minutes were conducted with managers and case managers (n = 4, including 22 participants), family physicians (n = 2, including 16 participants), nurses (n = 1, including three participants), community pharmacists (n = 2, including five participants) and CBO representatives (n = 4, including 25 participants). Table 1 presents the characteristics of the participants. The focus groups included two to eight participants. A total of seven to nine participants provides a balance between the number of interactions by participants and the variation of experiences and opinions, while more specialized topics work best with groups of five or six participants [47]. The small size of certain focus groups is due to the unavailability of some participants from the same category to gather at the same time and in the same place. Even in the smaller groups, interactions between the participants produced deeper discussions, thereby improving understanding [47]. Individual interviews and focus groups were conducted face-to-face by four master's level research assistants experienced in qualitative research (two with a background in social work, and two in anthropology). One research assistant facilitated the focus group while another took notes. The semi-structured topic guide used by the research assistants was informed by the literature review (including integration dimensions) and discussions across the research team to achieve the objectives of the study. Questions were adapted to the various categories of participants and validated by the research team members, including a patient partner. The Interview Guide is reported in the S1 File. Individual interviews and focus groups were recorded and transcribed verbatim. Excerpts were anonymized.

Table 1. Characteristics of the participants (n = 129).

Participants	**Patients**		**Health professionals**	**Managers**
Type of interview: n				
Individual interviews	25		20	13
Focus groups	0		9	4
Total of participants: n	25		69	35
Variables				
Gender: n (%)		Gender: n (%)		
Female	12 (48%)	Female	47 (68%)	26 (74%)
Male	13 (52%)	Male	22 (32%)	7 (20%)
Age (years): n (%)		Years of experience: (x̄)	12	7
18–40	3 (13%)	Profession: n (%)		
41–64	10 (33%)	Family physicians	32 (46%)	
65+	12 (50%)	Primary care nurses	3 (<4%)	
Educational level: n (%)		Pharmacists	9 (13%)	
None	1 (4%)	Community representatives	25 (36%)	
Primary	7 (29%)			
Secondary	15 (58%)			
College	1 (4%)			
University	0 (0%)			
Occupation: n (%)				
Full-time/part-time work	3 (13%)			
Full-time school	1 (4%)			
Unable to work due to health condition	9 (33%)			
Retired	10 (42%)			
Married	11 (46%)			
Single	8 (33%)			
Divorced/separated	4 (13%)			
Widowed	1 (4%)			
Income (CAN$): n (%)				
$0–$20,000	15 (58%)			
$20,000–$40,000	5 (21%)			
$40,000-$60,000	1 (4%)			
$60,000–$100,000	1 (4%)			

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Credibility (accurate description of the phenomenon) was ensured by asking open-ended questions, by allowing participants some latitude in what they wished to reveal and by the triangulation of informants. Data saturation was not targeted for each of the participant categories, but the diversity of the actors involved (triangulation) allowed for a comprehensive representation of the phenomenon and enhanced trustworthiness [41, 48].

Analysis

Experiences and opinions collected from the participants were analysed according to a mixed thematic analysis [49]. Consistent with the descriptive design, this approach helps to identify "codes" or labels that assign symbolic meaning to the raw descriptive information compiled during the study [49]. Four research team members took part in the analysis process according to three iterative stages allowing data-driven coding and categorization to identify emergent themes and trends: data condensation, data organisation and their interpretation [49]. First, data were categorized in themes identified according to Valentijn et al.'s taxonomy and conceptual framework [36, 37] (deductive) and other relevant information allowing us to achieve the research objectives (inductive). This step of data condensation was processed using NVivo software (Version 11). Second, tables were created to organise and synthesize the data, grouping them into a smaller number of themes (data organisation). Third, patterns were identified, described, and explained (interpretation). Three members of the research team validated each step of the thematic analysis process according to the investigator triangulation method [50].

This study received approval from the Ethics Review Boards of the Saguenay-Lac-Saint-Jean Integrated University Health and Social Services Centres. All informed consent was given in writing.

Results

Table 2 summarizes the results presented in the following section.

Clinical integration

Participants recognized the usefulness of the individualized service plan as a powerful tool to ensure a global understanding of the people's situation, focusing on their priorities and enabling the complementarity of health care and psychosocial resources.

> "Sometimes the individualized service plan is where you can really get to know the person a little more as a whole." (Focus group with CBO representatives)
>
> "Involving them [people with complex needs] as well as making them responsible for the overuse of services; whether by having them attend the individualized service plan meeting, or other such individualized references, I believe is empowering for these people." (Focus group with CBO representatives)
>
> "We developed an individualized service plan so that all the stakeholders on both the social and physical sides understand the consequences of my health problems and treatment. . . I can explain my background. I know my situation very well." (Individual interview with a patient)

The difficulty for CBOs to help people with physical pain was also mentioned and calls for collaboration between healthcare services, illustrating the complementarity of healthcare and community resources.

Table 2. Strategies, enablers, and barriers for community stakeholders' engagement in CMPs according to the Rainbow Model of Integrated Care.

Integration dimensions	Engagement strategies	Engagement enablers	Engagement barriers
Clinical Coordination of person-focused care in a single process across time, place and discipline	Use of the individualized service plan Care coordination by the case manager Person-focused intervention	Patients' involvement Global understanding of the patient Mutual understanding of roles Complementarity of health care and community resources	-
Professional Inter-professional partnerships	Use of the individualized service plan Inter-professional collaboration	Shared vision, collaboration, and consensus among providers Interdependence between hospital and community stakeholders Less services duplication Less contradictions in care planning	Lack of recognition of CBOs by certain hospital providers Time required to participate in an individualized service plan
Organizational Inter-organizational partnerships	Formal consultation mechanisms between hospital and CBOs Inter-organizational collaboration Decision makers and managers support	Knowledge of each other organizations involved in the program Concerted efforts	Lack of opportunities for community stakeholders to be involved in decision-making processes within CMPs
Systemic Policy arrangements	-	-	-
Functional Support mechanisms and communication tools	Financial, managerial, and informational support Formal communication channels between the hospital and community stakeholders	Access to the patient's information Staff stability Previous collaboration established between the case manager and community stakeholders	Different opening hours from one organization to another
Normative Cultural frame of reference mutually respected by all	Use of the individualized service plan	Individual openness to collaboration Common purpose towards frequent users of health services	Cultural differences in focus on physical vs psychosocial health Differences in bureaucratic structures and funding mechanisms

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The important role of case managers in care coordination across services at the clinical level has also been raised by a participant.

> "It definitely takes a conductor for this global coordination. The case manager is like the orchestra's conductor." (Individual interview with a family physician)

Community stakeholders and hospital providers both recognized and adopted the person-focused approach, which improves clinical integration and may enable collaboration and engagement between stakeholders.

> "The minute you hear the words 'vulnerable clientele' [. . .] It means . . . these people have special needs, and someone has to take care of them, no matter who. It may be a team, an individual, several people, a community, a society, a family, whatever [. . .] together with the client, with his or her experience, we will take him or her elsewhere." (Individual interview with a hospital manager)
>
> "You don't have to work for the system, to unclog the system, you have to work for the person. If you focus on that, maybe the solutions will be easier than passing the buck." (Focus group with CBO representatives)

Professional integration

Two main processes related to professional integration were described by participants: having a shared vision between providers focusing on the content of care and the development of an interdependence between hospital providers and community stakeholders. Again, the individualized service plan was outlined as an important tool to foster a shared vision, enabling consensus among stakeholders and reducing duplication of services. Community stakeholders recognized the added value of the collaboration. Providers from the hospital and community stakeholders also recognized that individualized service plans support the development of collaboration with CBOs.

> "Everyone is on the same page, everyone has a defined role, rather than sometimes duplicating services or contradicting each other. People cannot always come together, which is what individualized service plans allow them to do." (Focus group with CBO representatives)
>
> "We are all here to discuss the same patient. It's amazing how together we make a much greater difference than each of us on their own." (Individual interview with a community pharmacist)

However, a condescending attitude toward and lack of recognition of CBOs by certain hospital providers and the time required to participate in an individualized service plan were outlined as barriers to professional integration.

> "In terms of personality, there are some who will come to us and impose themselves as experts. 'Look here, I've been doing this for 25 years. . .' But not everyone is like that. There are others who arrive a little awkwardly, they are great to deal with. So that's it, there is also a lot of whoever you have in front of you." (Focus group with CBO representatives)
>
> "There is a lack of knowledge about the existence of community services, but once you know about them, you have to recognize the professional expertise within the community network [. . .]." (Focus group with CBO representatives)
>
> "I mean, it's a barrier that we have to take the time, in community pharmacies, to participate in an individualized service plan. It's a major financial hurdle [. . .]." (Individual interview with a community pharmacist)

Organisational integration

Organisational integration between healthcare services and community stakeholders in CMPs happened mainly through knowledge of each other and through concerted efforts between these organisations.

> "Of course, it requires a concerted effort, but the providers also need to know about the organisations' services, departments, and missions, whether through us or others. For example, for a patient who never comes to his appointments, because he has atypical hours, he sleeps during the day, there is street work, there are outreach services and community organisations that work at atypical hours, which could help us to remedy the situation as well as taking part in the individualized service plan." (Focus group with CBO representatives)
>
> "All these organisations [CBOs] are often useful for respite. And, often, when people live in isolation, if they don't know what to do, they come to the emergency department or their level of distress rises quickly. I believe that these organisations do have a complementary role." (Focus group with hospital managers)

> "I just wanted to add that there are a lot of community organisations in our mental health individualized service plans [. . .] There is a great collaboration. [. . .]
>
> I've been the coordinator since 2008, and it's amazing how much better our relationship with the community network gets every year." (Focus group with a coordinator and a case manager)

Lack of opportunities for CBOs and community pharmacies to be involved in decision-making processes within CMPs for people with complex care needs was reported as a significant barrier to their engagement. As suggested by some participants, CBOs and community pharmacies should be more involved in decision-making about these programs and especially about the way patients can be identified and supported. Formal consultation mechanisms between the hospital and CBOs were suggested to overcome this barrier.

> "[. . .] could a complex case committee not be set up, with the [health] network and with community organisations, so that we can work in collaboration rather than just one way." (Focus group with CBO representatives)

System integration

No direct processes concerning system integration were identified from the participants' narratives.

Functional integration

Information management and resource management were the only two functional integration- processes described by the participants. Knowledge of the individualized service plan by CBO representatives and pharmacists provides an overview of the patient's situation, so they can refer the patient or intervene more efficiently. For their part, patients do not have to repeat their stories to every care team member. Some other communication channels between the hospital and community stakeholders were recognized as promoting better access to the patient's information and to common knowledge that facilitates clinical, professional and organisational integration.

However, most of these communication channels relied on previous collaboration between the case manager and stakeholders involved. These narratives illustrate how both information management and resource management can influence functional integration and may demobilize stakeholders.

> "When we know people and we have a good relationship, we have the right information. When these people retire, change jobs, or leave the organisation, we lose it [. . .]. It is challenging because there is no established communication structure. There should be clear channels of communication and staff management that improve staff stability, but there is nothing, it's case-by-case. [. . .] The turnover rate means it changes all the time." (Focus group with CBO representatives)

Normative integration

Cultural differences between hospital and community stakeholders regarding the focus of the intervention (psychosocial vs healthcare needs) and differences in bureaucratic structures and funding mechanisms may affect community stakeholders' engagement.

> "I would tell you that, with the hospital, of course, we have to work together anyway, the partnership is still going well, but we have to work on it. Because, in fact, it's two different cultures, the way of doing things is different too. Of course, there is dissatisfaction in the way of doing things." (Focus group with CBO representatives)
>
> "There is a reality with regard to CBOs, which is that they are autonomous, they can do what they want, and then the funding, which is related to this among other things, means that, theoretically, we are not required to have relationships. Therefore, it depends more on the goodwill of the people who work there." (Focus group with CBOs representatives)

Despite these differences, the organization of individualized service plans can help stakeholders focus on a common purpose for frequent users of health services.

> "What we often realize in the individualized service plans is that we worked in different ways, in different directions, and the person was quite happy with that. Now, when we all go the same way, it's much simpler. The person is well supported, and we know where we are going. It works, it works." (Focus group with CBO representatives)

Discussion

There is growing recognition that integrating care can improve patients' outcomes, especially among those with complex health and social needs [25]. By ensuring communication and collaboration between professionals of various organisations, and the participation of every stakeholder, case managers are "searching for connections between the healthcare system and other human service systems to improve outcomes", which correspond precisely to the definition of integrated care as stated by Leutz [10]. Previous studies showed that promoting interorganizational collaboration faces a greater challenge than promoting interprofessional collaboration due to differences between corporate cultures, geographical distance, the multitude of processes, and formal paths of communication [51]. The results of this study confirm the gap between community stakeholders and CMPs due to these challenges and offer new insights into this engagement.

CBOs and community pharmacies wish to be engaged in CMPs. Their proximity to the population (physical presence in the living environment), their adaptability and plurality of service delivery, their knowledge of the daily users' situation and individual needs and goals, and their complementary knowledge, whether about pharmaceutical or psychosocial aspects can contribute significantly to improving the programs [52–55]. CBO and pharmacy stakeholders are also well positioned to help identifying people with complex care needs.

For community stakeholders, the individualized service plan remain the main ingredient of the CMP. The use of a multidisciplinary/interorganisational care plan is already recognized as an effective approach to aligning the goals of the different healthcare services and as an effective strategy to ensure positive program outcomes for people with complex health and social needs [56–58]. Community stakeholders believe that they can and should contribute to the individualized service plan. According to them, this contribution could improve global patient engagement, better access to patient information and interprofessional collaboration. However, cultural differences, as well as challenges in communication channels were raised as significant barriers to this contribution, as collaboration still often relies on a history of collaboration between involved parties [26, 37, 55, 59].

In response to these challenges, many participants outlined, as suggested by other authors [60], the importance of formalizing partnerships and communication channels. These improvements should span "over the full continuum of services as opposed to separate providers and sectors" [61], building on but going beyond previous collaborations. As observed by Fleury et al. (2014), a vulnerable population with complex needs evolving in a decentralized network needs more formal partnerships to improve the integration of services [62]. As one research participant mentioned, "Collaboration must become the norm". Hospital decisions should consider the inclusion of community stakeholders on CMP governance committees. To do this, community-based and person-focused paradigms of care must be strengthened [63] and community stakeholders must be considered as co-producers of care [64] and, ultimately, as co-builders of social policies [21] for people with complex needs. Decision makers must consider adequate funding [60] dedicated to community stakeholders participation in individualized service plans [65, 66] and their engagement in CMPs. In the same way, the programs need to be supported and pursued in a perspective of ongoing improvement.

Limitations of the study

The community stakeholders who participated in the interviews and focus groups did not all have direct exposure to the CMPs. Their variable experiences within the programs may have influenced the results. However, all community stakeholders were referred to the research team by a case manager, worked with the targeted clientele, had connections with the health and social services network and had a minimum of knowledge about the programs. Their contribution was still relevant to the study.

As mentioned, the Interview Guide was not formatted based on the Rainbow Model of Integrated Care. Although it is a robust framework, elaborated to provide all stakeholders' perspectives at all levels (macro, meso and micro) and internationally recognized in the field of integrated care, it remains difficult to use in the way it is formulated. For example, no system integration processes were identified from the participants' narratives, but this type of integration can be difficult to differentiate from organisational integration and may be less relevant to clinical stakeholders [36, 38].

Finally, the limited description of the settings where CMPs were implemented makes the transferability of the results difficult. However, the heterogeneity of the contexts (i.e. populations served by CMPs, their urban and rural environments, their size, the types of providers who participated) may increase the theoretical transferability.

Conclusion

While CMPs remain powerful tools for integrated care for people with complex needs, there is a persistent gap when it comes to fully engaging community stakeholders in case finding, as well as development and implementation of the individualized services plan. Formalized strategies to promote partnerships and better communication channels are needed, as well as the involvement of these stakeholders on governance committees at the healthcare system level.

Supporting information

S1 File. Interview guide.
(DOC)

S1 Checklist.
(DOCX)

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Integrating Mental Health Care Services Into HIV Comprehensive Care

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ABSTRACT

OBJECTIVES: HIV prevention strategies prioritize medication adherence among people living with HIV (PLWH). Of the 1.1 million PLWH in the United States, more than two-fifths are not virally suppressed and thus experience increased morbidity and mortality as well as transmission risk. Integrated care models are meant to address these gaps and often cite the importance of mental health care services (MHCS). However, research into the impact of integrating MHCS has been limited to those in homogenous treatment.

STUDY DESIGN: This study used an analytic observational cross-sectional design to achieve the above objectives.

METHODS: This study utilized a cross-sectional survey aimed to identify needs among PLWH in the Midwestern region of the United States and to stratify by both MHCS need and receipt. The survey, administered throughout 2018 in 12 HIV service organizations, was completed by PLWH receiving different supportive services. Comparative logistic regression models were calculated to identify the likelihood of nonadherence based on both MHCS receipt and need.

RESULTS: Of the 537 survey respondents, 20% reported receiving integrated MHCS, 8% reported needing but being unable to receive MHCS, and 72% reported not needing or receiving MHCS. Overall, 50% of the sample reported missing at least some HIV medication within the past 30 days. Individuals who needed but did not receive MHCS were more likely to report treatment nonadherence. No significant difference in adherence was identified between those who received MHCS and those who did not need MHCS.

CONCLUSIONS: Results suggest that continued assessment of needs and integration of MHCS into HIV care improves the likelihood of medication adherence. Further, our study highlights how systematically asking PLWH about their needs and connecting them to services may critically affect HIV management.

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HIV treatment adherence plays a critical role in the US National HIV/AIDS Strategy, which is ultimately aimed at reducing the number of new HIV infections by 75% within 5 years.[1] Adherence to antiretroviral therapy results in decreased likelihood of HIV-related morbidity and mortality and a 96% reduction in likelihood of viral transmission.[2,3] However, of the 1.1 million people living with HIV (PLWH) in the United States, only an estimated 63% are virally suppressed (HIV RNA < 200 copies/mL), signifying decreased treatment adherence.[4,5] The HIV integrated care model was developed to address these barriers to continued engagement in care and adherence. This system of care is developed to be individualized and community centered, which may leave PLWH without comprehensive treatment plans.[6-8] Mental health care persists as a common need among PLWH, with limited service availability.[9]

Psychiatric disorders are more prevalent among PLWH; however, those who are able to initiate and engage in active treatment plans often manage their HIV effectively.[10,11] Further, psychological distress symptoms are more common among PLWH who are not virally suppressed compared with those who are virally suppressed.[12] Thus, there are urgent needs to deliver mental health care services (MHCS) among this population. Identifying PLWH who are engaged in MHCS juxtaposed with populations who report needing but not receiving MHCS may help illuminate the role of repeated assessment across the HIV care network.

The aim of this study was to determine the association between reported MHCS need and medication adherence among PLWH to better understand how receipt of care may influence HIV management. Of particular interest were the PLWH who reported the need for MHCS yet did not receive such care.

METHODS

Data for this study utilized 2017 cross-sectional anonymous survey responses completed by PLWH who reside within a 12-county Midwestern region. This annual survey was developed by the region's Ryan White HIV/AIDS Program Planning Council and is distributed

TAKEAWAY POINTS

Mental health care is cited as an important component of integrated HIV care. However, previous studies are often limited to respective samples in homogeneous treatment plans. Among a sample of people living with HIV, our study finds that:

- unique differences exist between those in need of mental health care services and those receiving mental health care services,
- receipt of mental health care services significantly improves likelihood of medication adherence, and
- developing and utilizing methods to identify gaps in integrated HIV care allows for more precise understanding of needs and service delivery.

by HIV case managers within the region. This survey assesses which support service needs are currently important to PLWH in the region.

Inclusion criteria for this study included having previously received a diagnosis of HIV, being 18 years or older at time of survey, and receiving comprehensive HIV case management services funded by the Ryan White HIV/AIDS Program at 1 of 12 case management locations throughout the region. Respondents complete a cross-sectional needs assessment survey annually; thus, they both are familiar with and play an integral role in developing the survey items and protocols. Surveys were conducted as program evaluation of the support services in the region; thus, informed consent was not sought. The data were shared without any identifying information.

Within the survey, MHCS were defined per service guidelines outlined by the Health Resources and Services Administration and the HIV/AIDS Bureau.[13] This includes "psychological and psychiatric treatment and counseling services…provided by a mental health professional licensed or authorized within the State to render such services." Respondents were asked whether (1) they had received MHCS within the past 12 months and (2) mental health care was a service they needed but had not received within the past 12 months. Based on responses, individuals were stratified into 1 of 3 groups by MHCS need and enrollment: group 1, receiving MHCS within the past year; group 2, needing MHCS but have not received them; or group 3, not needing nor receiving MHCS within the past year. Individuals who chose contradictory responses were excluded from analysis. In final predictive modeling, included sociodemographic characteristics were age, gender, race/ethnicity, history of chronic homelessness, and history of incarceration, based on their previously identified modification of HIV medication adherence within current literature.[14,15] In addition, respondents were asked to identify from a list of 26 other medical and social services listed on the survey which services they needed and whether they were receiving them. The numbers of services chosen by each participant were summed and incorporated into the adjusted model to differentiate MHCS from overall gaps in integrated care.

An adapted form of the Basel Assessment of Adherence Scale was used to assess HIV medication adherence. The single-item question is shown to be accurate and reliable among participants who manage chronic disease medication.[16] Further, self-reporting adherence among PLWH is correlated with viral load measurements.[17,18] Respondents were asked to estimate how often they missed doses of prescribed HIV medication during the past 30 days with choices ranging from "none" to "daily." Responses were then dichotomously coded as (1) adherent (no missed doses) or (2) nonadherent (some missed doses). Although a continuous measurement of adherence typically explains a higher proportion of variability, dichotomization is appropriate when categorical data (eg, responses) are skewed and is consistent with similar research.[19]

Descriptive statistical tests of sociodemographics were conducted among the total sample along with each stratified group by MHCS need and receipt to better understand how the groups may differ. Three logistic regression models were completed to determine the crude likelihood of reporting nonadherence based on MHCS group. Models 1 and 2 compared individuals in group 1 and group 2 with group 3, respectively, and model 3 compared adherence differences between groups 1 and 2. A final adjusted model was developed to account for the sociodemographic characteristics previously identified to be associated with adherence. Significance was reported at $\alpha = 0.05$.

RESULTS

Of nearly 6000 PLWH receiving services within the region, 599 participants attempted the survey.[20] Of the total, 55 (9.2%) surveys were excluded from analysis because of missing or incomplete responses. A small portion (n = 7; 1.2%) were excluded because of contradictory responses regarding receipt of mental health care in the past 12 months. A total of 537 (89.6%) participants completed surveys that were included in analysis.

The mean (SD) age among the sample was 43.8 (11.4) years. Most of the sample identified as male (n = 372; 69.3%) and as a racial/ethnic minority (n = 382; 71.1%). One in 5 participants reported ever having experienced chronic homelessness (n = 106; 20%), and 12.5% reported ever having been incarcerated (n = 68). Participants chose a mean (SD) of 2.2 (2.5) services that they needed but were not receiving. Half the sample (n = 269; 50.5%) reported missing 1 or more doses of HIV medication within the past 30 days.

Among the sample, 105 participants reported receiving MHCS within the past year (19.6%), 43 participants reported needing but not receiving MHCS (8.0%), and 389 individuals reported not needing nor receiving MHCS within the past year (72.4%). Additional sample characteristics by MHCS need are detailed in **Table 1**.

Logistic predictive model details and comparisons are depicted in **Table 2**. Crude results reveal no significant difference in medication adherence between group 1 and group 3 (odds ratio [OR], 0.96; 95% CI, 0.62-1.48). Individuals in group 2 were significantly more likely to report nonadherence compared with individuals in group 3 (OR, 3.08; 95% CI, 1.51-6.29) and group 1 (OR, 3.2; 95% CI, 1.46-7.04).

TABLE 1. Sample Characteristics of People Living With HIV According to Mental Health Care Service Need and Receipt

	Group 1[a] (n = 105; 19.6%)	Group 2[b] (n = 43; 8.0%)	Group 3[c] (n = 389; 72.4%)	Total (N = 537)
Number of unmet service needs, mean (SD)	2.1 (1.8)	4.9 (4.8)	2.0 (2.1)	2.2 (2.5)
Age in years, mean (SD)	45.3 (10.3)	39.4 (10.8)	43.9 (11.7)	43.8 (11.4)
Current gender male, n (%)	58 (55.2)	37 (86.0)	277 (71.2)	372 (69.3)
Racial/ethnic minority,[d] n (%)	76 (72.4)	26 (60.5)	280 (72.0)	382 (71.1)
History of chronic homelessness, n (%)	27 (25.7)	15 (34.9)	64 (16.5)	106 (19.7)
History of incarceration, n (%)	17 (16.2)	7 (16.3)	44 (11.3)	68 (12.7)
Missed ≥ 1 dose of HIV medication in the past 30 days, n (%)	49 (46.7)	32 (74.4)	188 (48.3)	269 (50.1)

[a] Received mental health care services within the past year.

[b] Needed but did not receive mental health care services within the past year

[c] Reported not needing or receiving mental health care services within the past year.

[d] Nonwhite, non-Hispanic.

TABLE 2. Likelihood of Missing HIV Medication Within Past 30 Days Based on Mental Health Care Service Need and Receipt[a]

	Model 1 Crude OR[b]	Model 2 Crude OR[b]	Model 3 Crude OR[b]	Model 4 Adjusted OR[b]
Group 1[c]	0.96 (0.62-1.48)		Reference	0.99 (0.62-1.58)
Group 2[d]		**3.08 (1.51-6.29)**	**3.21 (1.46-7.04)**	**3.09 (1.37-6.97)**
Group 3[e]	Reference	Reference		Reference
Number of unmet service needs				0.95 (0.88-1.03)
Age in years				**0.97 (0.95-0.98)**
Current gender male				1.12 (0.75-1.69)
Racial/ethnic minority				1.23 (0.84-1.92)
History of chronic homelessness				**1.84 (1.14-2.97)**
History of incarceration				1.61 (0.90-2.91)

OR, odds ratio.

[a] Bold entries indicate significance at $\alpha < 0.05$. Model 1 indicates no significant difference in medication adherence between group 1 and group 3. Model 2 indicates group 2 is significantly more likely to report nonadherence compared with group 3. Model 3 indicates group 2 is significantly more likely to report nonadherence compared with group 1.

[b] OR calculated from exponentiated β and 95% CIs.

[c] Received mental health care services within the past year.

[d] Needed but did not receive mental health care services within the past year.

[e] Reported not needing or receiving mental health care services within the past year.

Upon adjusting for age, gender, race/ethnicity, history of homelessness, history of incarceration, and overall unmet service need, individuals in group 2 were significantly more likely to report nonadherence (adjusted OR, 3.09; 95% CI, 1.37-6.97). In addition, older individuals were less likely to report being nonadherent for every year of age increase (adjusted OR, 0.97; 95% CI, 0.95-0.98), and individuals who reported experiencing chronic homelessness were significantly more likely to report nonadherence (adjusted OR, 1.84; 95% CI, 1.14-2.97).

DISCUSSION

These findings suggest the importance of routine assessment and linkage to supportive services to achieve HIV viral suppression. This study identified that PLWH who report needing but not receiving MHCS are significantly more likely to report nonadherence with HIV medication compared with both individuals who received MHCS and individuals who reported not needing MHCS. This increased likelihood of nonadherence among group 2 remained even after adjusting for sociodemographic characteristics and history of homelessness and incarceration. Whereas MHCS need and receipt were found to be significantly associated with medication adherence, other documented unmet service needs were not associated with medication adherence in the adjusted model.

Although HIV integrated treatment plans are meant to address adherence challenges, a large portion of PLWH remain virally unsuppressed.[21] These results identify the importance of routine assessment and integrating an MHCS component into HIV care models. Further, this study found that MHCS need was more relevant to medication adherence than other unmet needs. This highlighted the unique need for MHCS among PLWH, one that will require additional support from integrated care providers to implement. Although our findings are aligned with those of similar studies, we believe our research is unique and adds to the discourse because of the emphasis on routine assessment and referrals in integrated care models.[22,23]

Limitations

Limitations and alternative explanations were explored in an effort to more effectively contextualize our findings. Although self-reported data are commonly utilized in similar research, more vigorous methods of clinical data collection are available, yet not available to the study team.[19] However, by utilizing these self-reported data, we were able to capture and empower the voices and unique experiences of PLWH.[24] Future studies would benefit by comparing our findings with additional sources of data. Further, this study did not distinguish between types of mental health care treatment. However, these findings offer a novel introduction that effectively argues for the inclusion of routine assessments for the need for MHCS and their provision within integrated care models. Insights could be gained from additional research that examines the efficacy of different types of mental health care treatment and the association of those treatments' effectiveness with HIV outcomes.

CONCLUSIONS

Many PLWH continue to struggle with complex challenges and needs that contribute to increased transmission rates among populations.[25] Continuing to identify more effective components of integrated care models will aid in addressing these inequities. This study identifies that MHCS is one of those components. ■

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The Impact of Psychological Status, Social Well-Being, and Physical Function on Healthcare Utilization

This editorial comments on the articles by Cheng et al. and Straatmann et al. in this issue.

Two articles[1,2] in this issue explore the impact of psychological, social, and functional factors on unplanned hospitalizations and other types of healthcare utilization. The article by Straatmann et al[1] is based on data from the Swedish National Study on Aging and Care in Kungsholmen and evaluates 2139 older adults over 4 years. The authors developed standardized indexes of psychological well-being (integrating life satisfaction and positive and negative affect) and social well-being (including social connections, social support, and participation) and hypothesized that older adults with high psychological and social well-being would have a lower risk of unplanned hospital use, and individuals with both high psychological and high social well-being would have the greatest protective effect against unplanned hospital use. The hypotheses were supported in this study. Specifically, when controlling for age, sex, education and occupation, health status, personality based on the NEO Five-Factor Inventory (which describes individuals as being in one of three categories: extraversion, neuroticism, and openness),[3] and alcohol and nicotine use, higher levels of psychological well-being were associated with fewer unplanned admissions and fewer hospital days. Psychological well-being was defined by the research team to include valid assessments of life satisfaction and positive and negative affect. Evaluated alone, social well-being (based on an assessment that included social connections, social support, and social participation) was not associated with hospital utilization. There was, however, a combined effect such that those with high levels of both psychological and social well-being showed the lowest rates of unplanned hospital admissions and shorter lengths of stay.

These findings make good logical sense, although it is useful to consider closely what is actually being measured with regard to psychological and social factors. The authors refer to their assessment as “psychological well-being,” although it seems what they really measured was resilience. The measures used to evaluate psychological well-being were the Life Satisfaction Index A[4] and the Positive and Negative Affect Schedule (PANAS).[5] The components of both of these measures are consistent with the definition of and personality components of resilience. Specifically, the Life Satisfaction Index A considers zest vs apathy; resolution and fortitude; congruence between desired and achieved goals; positive self-concept; and mood tone. The PANAS measure evaluates the following positive affect behaviors within individuals: active, inspired, determined, alert, and enthusiastic. Negative affect was also evaluated and included the extent to which a person was distressed, upset, scared, or nervous. By definition, resilience is “the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress.”[6] Being resilient indicates that the individual has the human ability to adapt in the face of tragedy, trauma, adversity, hardship, and ongoing significant life stressors.[7] The same factors measured in this study are considered to be factors or qualities within individuals that are associated with resilience. These include such things as positive interpersonal relationships, building social connectedness with a willingness to work with others, strong internal resources, having an optimistic or positive perspective about life and challenges encountered throughout the lifespan, maintaining realistic expectations, setting achievable goals and working toward those goals consistently, high self-esteem or self-concept, high self-efficacy, and determination.[8-10] Thus, the findings from this study support the need to continue to focus on developing interventions to strengthen resilience. In so doing, we may be able to facilitate the behaviors needed to remain at home following hospitalization and assure short lengths of stay when hospitalized. These behaviors include engaging in function and physical activities while hospitalized and in the posthospitalization period, adhering to appropriate treatment recommendations, and consuming appropriate nutrition and fluid intake.

The lack of significance between social well-being (ie, social connections, social support, and social participation) and unplanned hospitalizations and lengths of stay was likewise not surprising. Social well-being, as measured in this study, focused on the individual’s social network, whether the individual was satisfied with that network and the material or psychological support provided, the sense of affinity with the individual’s social network, and the individual’s participation in social activities. The evaluation did not indicate what the “social support” or caregiver may have done with regard to care giving, what his or her skill set and comfort was with providing care in the home

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setting, and ability/efforts to access timely and quality medical care. It is these latter social support factors that are likely to have a greater influence on hospitalizations. When the older individual is home alone or has limited social supports, he or she may have to perform personal care activities, meal preparation, and other household activities and in so doing will regain strength and function. Conversely, the older individual may have a caregiver who does not know how to optimize nutritional intake and thus the older adult may become malnourished, weak, and sedentary. Unfortunately, caregivers sometimes take over care tasks that the individual can and should do.[11] This causes further deconditioning and decline in function, which can contribute to complications, such as falls and infections, that require hospital admissions.

With regard to social supports, a recent report by AARP, Home Care Revisited[12] noted that almost half (46%) of family caregivers performed medical/nursing tasks for care recipients, including medication management, wound care, use of monitors, managing incontinence, or using specific medical equipment. The comfort and skill level of these individuals might be more likely to contribute to a need for a hospital readmission than simply whether the individual had a social network. With the increased complexity of care needed posthospitalization due to shorter hospitalizations and more and more procedures done in outpatient settings (eg, joint replacements), a greater focus on caregiver skills and comfort with providing complex care is needed to evaluate the impact that this has on rehospitalizations. Interventions then could be implemented to improve caregiver training during the inpatient stay or following any type of procedure requiring postprocedure care. These interventions will need to consider the complex needs of the person with dementia, who was not included in the study by Straatmann et al,[1] but who is twice more likely to be hospitalized[13] and to experience more readmissions as compared to those without cognitive impairment.[14]

The study by Cheng et al[2] focused on the relationship between physical function and healthcare utilization over a 2-year period. Healthcare utilization was based on data from the Medical Expenditure Panel Survey to include counts of care provided in the inpatient setting, emergency department, outpatient care, home health services, and "other medical visits." Participants represented a weighted total of 26 809 552 individuals in the Lifestyle Interventions for Elders Trial.[15] Physical function was measured based on verbal report using the Physical Component Score from the 12-item Short-Form Health Survey.[16] This measure addresses the impact of health (including mental health and factors such as pain) on physical activity (eg, routine daily activities, occupational activities, and housework). The findings from this study noted that those with the lowest functional status had the most medical visits and highest healthcare expenditures. The authors go on to suggest, based on these findings, there is a need to have primary care providers encourage physical activity for older patients. While encouraging physical activity is certainly a core geriatric principle and should be part of any care interaction with older adults, the findings from this study do not provide evidence to support the value of physical activity with regard to decreasing healthcare utilization. It is possible that increasing physical activity, if not done appropriately, could result in increased healthcare utilization. For example, although screening older adults prior to engaging in moderate levels of physical activity is not recommended,[17] there are still some physical activity resources and programs for older adults that require the individual be screened by a healthcare provider prior to engaging in physical activity.

If providers and older individuals are not guided appropriately, engaging in the wrong types of activities might contribute to muscle strains and pain that result in a healthcare provider visit. Furthermore, there is a tendency to underestimate the potential to engage the older adult in physical activity due to preconceived ideas on the part of the clinician and/or a history of underperformance due to intrinsic and environmental conditions. Thus, an evaluation of the person's capability is critical to maximize physical activity and functional performance for older adults at varying levels of physical and cognitive status. Therefore, simply making recommendations for physical activity without appropriate education on the part of healthcare providers may not decrease healthcare utilization. Done correctly and guided by resources and guidelines such as those that are part of the Exercise Is Medicine initiative[18] can help older individuals to maintain function and may help to prevent initial hospitalizations or rehospitalizations and decrease the need for other types of healthcare utilization.[19]

The "clear and measurable differences" in utilization of healthcare found between individuals with different levels of function in the study by Cheng et al[2] does provide us with support for some important next steps. As the authors note, these findings are correlational and not causal. Future research needs to engage individuals with a wide range of functional abilities in physical activity and measure this activity with objective measures, such as some type of accelerometry. Accelerometry data would allow for testing of the impact of sedentary behavior vs light, moderate, or vigorous activity on healthcare utilization. Further, while the study by Cheng et al[2] included several covariates (eg, demographic data, socioeconomic information, and comorbidities), the factors in the study by Straatmann et al[1] (ie, psychosocial variables, such as resilience and social supports), along with cognitive status, medications, disease severity, pain, fear of falling, and care preferences, among others, should also be considered.

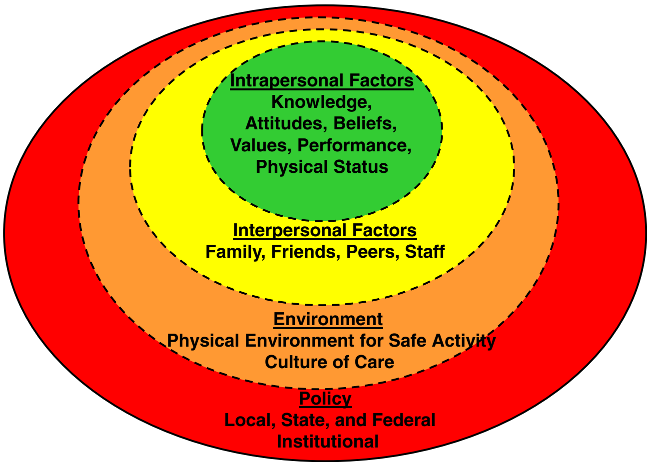

Figure 1. Social Ecological Model.

The findings from these two studies indicate that healthcare utilization is influenced by multiple factors, and these are probably best addressed guided by a Social Ecological Model[20] (Figure 1). The Social Ecological Model addresses intrapersonal factors, interpersonal factors, the environment, and policy. Future work should focus less on simply requiring that patients return to a healthcare provider within 2 weeks of discharge from the hospital and focus more on building resilience among older adults and their caregivers, providing caregivers with the appropriate education and resources to provide the home care that is needed, and encouraging older individuals to decrease time spent in sedentary activity, participate in functional activities, such as bathing and dressing, and increase time spent in physical activity with the goal of achieving 30 minutes daily of moderate-level physical activity or the level of activity that is possible given underlying capability.

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Telehealth and texting intervention to improve HIV care engagement, mental health and substance use outcomes in youth living with HIV: a pilot feasibility and acceptability study protocol

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ABSTRACT

Introduction Youth and young adults living with HIV (YLWH) experience worse clinical outcomes than adults and high rates of behavioural health challenges that impact their engagement in care and adherence to antiretroviral therapy. This study in the San Francisco Bay area aims to evaluate the feasibility, acceptability and preliminary clinical outcomes of a 12-session telehealth counselling series provided to 80 YLWH, including education, motivational enhancement and problem-solving around HIV care, mental health, substance use and other challenges. Findings will provide information about benefits and challenges of telehealth counselling for YLWH and will guide the development of new technology-based strategies for care.

Methods and analysis The Youth to Telehealth and Text to Improve Engagement in Care study is a pilot randomised, crossover trial examining the feasibility and acceptability of a telehealth counselling intervention consisting of twelve 20–30 min weekly sessions focused on identifying and problem-solving around barriers to HIV care access and adherence and on addressing mental health, substance use and/or other issues. Participants also receive text messages for check-ins, appointment reminders and to improve engagement. Participants complete quantitative online surveys at baseline, 4 and 8 months and qualitative exit interviews. Clinical outcomes, including plasma HIV RNA and CD4+ cell count, are collected from medical records. Study staff will explore outcomes of the intervention using quantitative and qualitative methods.

Ethics and dissemination This study and its protocols have been approved by the University of California, San Francisco (UCSF) Institutional Review Board. Study staff will work with the UCSF Center for AIDS Prevention Studies' Community Engagement Core and the Youth Advisory Panel to disseminate results to the community, participants and the academic community.

Trial registration NCT03681145.

Strengths and limitations of this study

- The use of iterative refinement of the intervention manual throughout this pilot study increases the study's potential impact and acceptability among participants.
- The study's counselling intervention is significant in its integrated HIV and behavioural health focus, which is tailored to the participant's baseline HIV knowledge, mental health status and substance use.
- The use of video chat and text messaging modalities for delivery of HIV engagement, mental health and substance use counselling with youth living with HIV is important, reduces the time burden to the clinician and patient and challenges the current delivery of healthcare.
- By examining the acceptability of a fully online versus hybrid in-person online session delivery, we will be able to determine if this intervention can be offered completely remotely, which will in turn increase the geographic reach for the delivery of this intervention.
- This pilot study is limited due to its small sample size, and the data generated from this study may not be generalisable to older individuals and those not living in the San Francisco Bay Area.

BACKGROUND

Youth and young adults aged 18–29 years living with HIV (YLWH) have unique challenges with HIV diagnosis, access and maintenance of care. In 2016, in the USA, youth aged 13–24 years accounted for about 21% of all new HIV infections.[1] Among those aged 13–29 years and living with HIV, only 41% were estimated to be aware of their HIV status. In 2014, of those diagnosed with HIV, only 62% accessed HIV medical care within the first year; of those, 43% were retained in HIV care, and 54% had a suppressed HIV viral load.[2] Access to care and antiretroviral therapy (ART) is crucial for the health of YLWH; high levels of ART adherence is critical for attaining HIV treatment goals including sustaining suppressed HIV viral load, decreasing risk of developing drug-resistant strains of HIV, reducing the risk of HIV transmission to others and improving overall health.[3–5]

Mental health and substance use challenges are prevalent in YLWH, though few studies have been conducted on behavioural health issues in YLWH. One study found that 18% of YLWH who were in care had clinically significant psychological symptoms such as depression or anxiety.[6] Another study of 1706 YLWH found that 42.6% reported mental health concerns at a clinically significant level. Of those reporting these symptoms, only 39.7% reported receiving mental healthcare services in the past year, and 21.9% reported taking medications for mental health conditions.[7] Additionally, in one sample of 12- to 26-year-olds living with HIV, 32% used tobacco, 27% used marijuana, 21% used alcohol, and 22% used other illicit substances.[8]

Mental health and substance use challenges have been shown to negatively impact HIV medication adherence and clinical outcomes across the continuum of HIV care for YLWH.[9 10] For example, in one systematic review and meta-analysis, those with depression symptoms had 42% lower likelihood of achieving 80% or higher ART adherence compared with those without depression.[11] Another found that of those not taking ART, the odds of reporting clinically significant symptoms were three times as high as those on ART, showing the strong relationship between mental illness symptoms and ART uptake and adherence.[12] Another review found that depression and anxiety symptoms in YLWH were strongly associated with ART non-adherence.[13] Additionally, the review found that higher alcohol use in the past week and substance use in the past 3 months were also predictive of poor adherence.

There are few evidence-based counselling interventions for YLWH that address behavioural health factors impacting adherence to HIV care.[13] Interventions developed for adults have shown to be effective in improving depressive symptoms as a method of improving ART adherence.[13] However, young adults differ in multiple ways, including their technology use habits, creating an opportunity for the application of technologies to behavioural health interventions.

As 98% of people aged 18–29 years have a mobile telephone and over 85% have a smartphone, telephone-based interventions are potentially accessible for the majority of YLWH.[14] Most traditional counselling interventions are provided in person and a clinical setting; engaging in these counselling sessions may be a barrier for YLWH who experience transportation or financial issues, stigma or shame around accessing treatment or other challenges.[15] In our formative work, YLWH reported that health-focused mobile interventions could overcome concerns about their ability to effectively and openly communicate with their providers.[16] One survey similarly found that 60% of millennials would be interested in video chat interactions with their medical provider instead of attending in-office appointments.[17]

Several HIV care adherence interventions have been developed for individuals living with HIV, though most are for adults of all ages rather than YLWH. Few of the interventions specifically developed for YLWH use telehealth, texting or other mobile technologies as the platform for intervention delivery.[18] Although these methods have been shown to be promising in improving ART adherence and linkage to care in adults living with HIV, they have been minimally studied in YLWH.[19]

The existing literature on telehealth and texting platforms for HIV-related interventions for YLWH show promising results and highlights the need for additional research in this area.[13] One text message medication reminder system for adolescents and YLWH was shown to be feasible, efficacious and satisfactory to participants.[20] However, a study of 15– to 22-year-old YLWH found that neither a one-way or two-way text messaging intervention significantly improved HIV medication adherence.[21] This highlights the need for additional research on the effectiveness of interventions that combine text messaging with other elements, which may improve efficacy.

In this paper, we describe the protocol for a study to examine the feasibility and acceptability of a novel 12-session telehealth counselling series and accompanying text messages to improve engagement in HIV care, mental health and substance use outcomes. The Youth to Telehealth and Text to Improve Engagement in Care (Y2TEC) intervention is novel in its combination of telehealth and text messaging and strategic integration of three foci (ie, engagement in HIV care, mental health and substance use). We will identify whether these methods are feasible and acceptable to YLWH and will examine preliminary clinical and behavioural outcomes of the intervention. We anticipate that Y2TEC will be feasible and acceptable for counselling YLWH and that participants will show preliminary evidence of improvement in clinical and behavioural outcomes.

METHODS/DESIGN

Study overview and design

The Y2TEC study is a single-site randomised pilot study with the primary aim of examining the feasibility and acceptability of a 12-session telehealth and text message–based counselling series for YLWH. The secondary aim is to evaluate the preliminary impact of the intervention on improved engagement in HIV care, enhanced mental health and reduced substance use for YLWH. The University of California, San Francisco (UCSF) Institutional Review Board (IRB) has reviewed and approved this study. The intervention was designed based on the results of our formative mixed-methods and qualitative research on youth-friendly HIV counselling methods. The intervention is delivered to participants in two condition groups (ie, intervention and waitlist control) via remote telehealth sessions delivered over 4 months, with a crossover design (see table 1). The overall duration of participation is 8 months.

Table 1 Study overview

I=intervention arm participants W=waitlist arm participants X=all participants	Months								
	0	1	2	3	4	5	6	7	8
Screening/enrolment									
Telephone screening	X								
Informed consent		X							
Assessment surveys									
Baseline survey		X							
Follow-up surveys					X				X
Satisfaction and acceptability questionnaire					I				W
Counselling sessions									
Weekly counselling sessions (12)		I	I	I	I	W	W	W	W
Bidirectional text messages									
Monthly check-ins			W	W	W		I	I	I
Session ratings		I	I	I	I	W	W	W	W
Goal reminders		I	I	I	I	W	W	W	W
Session reminders (24 hours and 15 min before telehealth session)		I	I	I	I	W	W	W	W
Community events and resources		X	X	X	X	X	X	X	X
Exit interviews									
Satisfaction survey					I				W
Qualitative exit interviews					I				W

Study setting

Participants are recruited from the San Francisco Bay Area. Participants consent to the study and complete their initial baseline survey in person in a private office at a community-based location or at UCSF's Center for AIDS Prevention Studies. All other study communications are remote via the video chat platform, text messages and telephone calls.

Study participants

The study sample will consist of 80 individuals aged 18–29 years living with HIV, who live in and receive medical care in the greater San Francisco Bay Area. We have chosen to include young adults in this age range as they are in a distinct developmental phase with unique needs and challenges compared with minors or those aged older than 29 years. Other inclusion criteria include English-speaking, willing and able to provide informed consent and have access to a mobile telephone with text messaging capability. Those planning on moving out of California in the next 8 months or with evidence of severe cognitive impairment or active psychosis that may impede their ability to provide informed consent are excluded.

Sample size justification

NCSS and PASS will be used to compute the minimum detectable effect (MDE) sizes, assuming alpha=0.05, power=0.80 and n=64, reflecting anticipated attrition of 20%.[22] For estimates of means and proportions for feasibility and acceptability measures, the minimum detectable distance from the estimate of the proportion to the upper or lower confidence limit is 12.7%, assuming a target of 70% feasibility and acceptability. For means, the standardised distance to the limit is 0.25. For primary preliminary outcome analyses proposed to compare means of continuous outcomes across the intervention and control groups at 4 months, the minimum detectable standardised mean difference d is 0.30. These MDEs are between cutoffs for small (d=0.20) and medium (d=0.50) standardised mean differences suggesting our study is powered to detect small to medium effects.[23]

Patient and public involvement

Prior to the design of this study, we conducted formative research with healthcare providers and patients (Saberi et al, under review), which helped us refine our research questions, study design and outcome measures. We asked YLWH about optimal methods for intervention delivery and considered the requests of several participants to have an initial session face-to-face with the counsellor. Additionally, we involve participants in study recruitment by encouraging active participants to refer others and providing a $25 incentive to both the referee and referred. We will assess the effects and burden of the intervention by the participants themselves through our quantitative survey and qualitative exist interviews after the intervention. We will work with our Youth Advisory Panel and Community Action Board to disseminate the study's results to participants and the community.

General study procedures

Recruitment methods

Participants are recruited through in-person outreach at clinical and community sites serving YLWH, emails to clinics and providers, flyers posted at health clinics and community-based organisations, targeted online advertisements on Instagram, Craigslist, Facebook and Grindr and recontacting participants from prior studies who had expressed interest in being contacted about future studies. Finally, a participant referral method is used, and a $25 incentive is provided to both the referring participant and new participant.

Eligibility screening

Study staff provide a brief overview of the study to prospective participants, answer any questions and complete an eligibility screening on the telephone. Those who meet the inclusion criteria and are willing to participate in the study are asked for a photo ID to verify their date of birth and proof of HIV status (a letter of diagnosis, laboratory results or HIV medication prescription) via a photo text-messaged to the study telephone or by bringing these documents to the initial in-person visit.

Consent and enrolment procedure

The enrolment visit will be completed in person with a study staff member. Participants review the electronic consent form (see online supplementary appendix A) with a study staff member in a private setting. Individuals who are eligible and agree to participate electronically sign the consent and a medical release form using Qualtrics (Provo, UT, USA; version March 2017) an online survey platform and are provided a copy of the Experimental Subject's Bill of Rights.

Baseline survey

Participants then complete the online baseline survey, which takes approximately 30–45 min. Study staff then help participants download a secure video chat mobile application (ie, Zoom, a (Health Insurance Portability and Accountability Act [HIPAA]–compliant video chat platform) on their telephones. Study staff demonstrate how to set up privacy settings on mobile telephones, such as keeping text message previews from showing up on locked screens and adding a security code to lock the telephone.

Randomisation

Following the baseline survey, research staff randomly assign participants to one of two condition groups (ie, intervention or waitlist control) with a prenumbered sealed envelope. Randomisation is done using SAS (version 9.4) based on randomly permuted block sizes to ensure equal-sized groups, and all study staff are blinded to the randomisation order. Approximately 40 participants will be randomised to the immediate intervention condition and receive their first session in person; about 40 participants will be randomised to the waitlist control condition for 4 months after study enrolment and then cross-over to the treatment arm and receive the study intervention entirely remotely with no in-person session with the counsellor. The counsellor and clinical research coordinator will not be blinded to the randomisation condition, as treatment will be prescribed as a result of the condition.

Participant retention

A number of steps are taken to retain participants throughout the study period. Participants are asked for multiple forms of contact information (including emergency contacts, clinical contacts and social media contacts) at the initial visit to prevent loss of contact. They receive three monthly follow-up text messages during the waiting period to confirm their contact information, appointment reminder text messages 24 hours and 15 min before scheduled counselling sessions, birthday text messages and a weekly text message with free fun local activities to facilitate rapport-building (see table 2).

Participants' Incentives

Participants receive up to $310 for completing all study activities, including payments for each counselling session that gradually increase throughout the study (in $10–$25 increments). Participants are given a ClinCard, a reloadable debit card and instructions for use at the initial visit. Participants are also entered into two raffles for chances to win $25 Amazon gift cards when they confirm their contact information or answer two session rating questions after each telehealth session. Additionally, participants who refer others to the study are paid $25 per successful recruitment.

Risks to participants

All risks to participants are monitored by study staff and documented at each session and study assessment. Study staff are trained to thoroughly explain these risks to participants as well as the steps taken to ensure privacy and confidentiality of all information. Safety-related risks to participants could include discomfort due to the sensitive nature of questions in study surveys including substance use, HIV health-related issues and mental health. Non-clinical study staff conducting interviews and participant communication refer to clinical study staff if participant distress is identified. Clinical staff delivering the intervention are trained to assess distress level of participants and refer to established protocols for any participant crisis. If a participant requires treatment due to distress, this will be determined by clinical staff; they will be referred to appropriate services following the crisis protocol, and the principal investigator (PI) will be informed.

Table 2 Text messages

Message	Schedule	Text and response
24 hours Reminder* (A)	24 hours before appointment	If Y: 'Thank you for confirming, Please text us with any questions'. If N: 'Thank you for replying, we will contact you to reschedule'.
15 min Reminder (A)	15 min before appointment	'UCSF Team: Appointment Reminder: See you in 15 min, here is the link (zoom link)'.
Resource (M)	As needed	'UCSF Team: Resources: Here are the resources you requested (link to resources)'.
Goals* (M)	Three business days after session	'UCSF Team: Goals: Were you able to attempt your goal? Yes Or Not Yet'. Response: 'Got it!'
Free Stuff (A)	Weekly	'UCSF Team: Fun Free Stuff: Enjoy Free Yoga in the Park this Saturday from 10 to 11 am, Downtown Oakland. Here's the link (website)'.
Monthly Check-in* (A)	Monthly during waiting period	'UCSF Study Team: Update or confirm your contact info for a chance to win one of 5 $25 Amazon e- Gift cards at the end of the study. Has your phone number or email address changed? Please reply 1 Yes 0 No' If yes: 'Please send us your updated phone number and email address.________ Thank you! You have been entered in the raffle, good luck!' If No: Thank you! You have been entered in the raffle, good luck!'
Survey Link (M)	Baseline, 4 and 8 months	'UCSF Team: It's time for your survey. Click on the link below to complete the feedback survey and receive $10. Thank you! (Survey Link)'
Session Rating* (A)	After each session	'UCSF Team: Please tell us about the session today for a chance to win one of five $25 Amazon e-Gift cards at the end of the study: 1- I felt heard, understood, and respected by the counselor: a. Strongly agree b. Agree c. Neither agree nor disagree d. Disagree e. Strongly disagree 2- Overall, today's session was right for me: a. Strongly agree b. Agree c. Neither agree nor disagree d. Disagree e. Strongly disagree' Response: 'Thanks for your responses! Please let us know if you have any additional comments by texting us'.
Session Completion (M)	After completion of all sessions	'Congratulations on completing the 1 st half of the Y2TEC study! Next, you will receive a survey on xx/xx/xx & a final survey on yy/yy/yy. Please let us know if you have any questions. Thanks!'
Waiting Period Completion (M)	After completing waiting period	'Congratulations, you have finished the 1 st half of the Y2TEC study! Next, you will receive a survey on xx/xx/xx & we will contact you to schedule your 1 st video chat session after you complete your survey. Please let us know if you have any questions. Thanks!'
Birthday Message (M)	On participant's birthday	'UCSF Team: Happy Birthday, we are sending you all our best wishes for a very happy birthday today, cheers!'
Away Message (A)	After hours and holidays	'Thank you for your message! The Y2TEC Study staff are out of the office until XX/XX/XX and will respond after this date. If this is an emergency, please call 911.'
Study Referral (M)	As needed	'UCSF Team: Participants can receive up to $310 for completing all study activities plus $25 per person they refer who enrolls in the study!'

*Bidirectional.
(A)=Automated message.
(M)=Manually sent message.

Adverse events and auditing

The study staff monitor postsession participant ratings (via text message) as one method for identifying those who may have experienced an adverse event. If a participant reports low satisfaction with the intervention, study staff contact them in a timely manner to determine what occurred in the session. Study staff also provide participants with the study mobile telephone number to spontaneously report any adverse events or unintended effects of the intervention. Any adverse events will be documented on an adverse event form, and follow-up will be tracked. The form along with any session notes with details will be reported to the IRB by the PI within 10 working days. The team of investigators will also meet weekly to audit and discuss general trial conduct–related issues.

Protocol amendments

Protocol amendments will be shared with all stakeholders as they occur. Study staff communicate protocol modifications to investigators during monthly meetings, submit changes to www.clinicaltrials.gov as needed, submit IRB modifications and communicate changes to regulators during meetings every 6 months or via email as needed.

Intervention procedure

The 12-session telehealth series is delivered by a trained behavioural health professional (such a social worker, psychologist or psychotherapist), referred to as the 'counsellor' within the context of this study. Sessions use problem-solving, information-motivation-behavioural skills and motivational interviewing and focus on engagement in HIV care, mental health and substance use.[24–26] Telehealth sessions are completed via a secure video chat platform, Zoom, and text messages are sent via a secure encrypted, HIPAA-compliant platform called Mosio.

Series overview

Participants in the intervention arm meet with the counsellor in person immediately after enrolment, and the waitlist control arm participants meet with the counsellor via video chat after 4 months. Before the first meeting, the counsellor reviews the participant's most recent assessment survey responses to determine the participant's level of acuity and tailor appropriate session dosage. Mental health acuity is determined through the Patient Health Questionnaire (PHQ) 9 and PTSD Checklist (PCL); substance use acuity is determined through the Alcohol Use Disorders Identification Test (AUDIT) and Alcohol, Smoking and Substance Involvement Screening Test (ASSIST); HIV care acuity is calculated by a measure of HIV knowledge as well as current participant utilisation of HIV care services and antiretroviral medications. During the first session, the counsellor assesses the participant's needs and identifies current gaps in knowledge and motivation regarding mental health, substance use and HIV care. The first three to six of the remaining 11 sessions cover core psychoeducational and health literacy–promoting content around engagement in HIV care, mental health and substance use challenges and treatments. Those with higher acuity receive two foundational psychoeducational modules rather than one in each of the three areas, amounting to a maximum of six core educational sessions.

The remaining sessions use an integrated behavioural health and HIV care– focused approach to further the conversations initiated in the core sessions. At the beginning of these sessions, the participant and counsellor choose from a list of topics identified in the first session, including HIV care, mental health, substance use, lifestyle health, social support, family of origin, romantic and sexual relationships, self-identity and disclosure, subsistence needs (housing, money and resources) and education and vocation. These sessions can be done in any order and repeated as needed. If a participant is in crisis and unable to be redirected to these options, a 'wildcard' session focused on crisis response and safety planning may be held. The final session includes reviewing the content covered and goals achieved in the previous sessions, identifying unmet needs, accessing community-based resources and learning strategies for maintaining changes.

Scheduling sessions

Four months are allocated to complete the 12 weekly counselling sessions to allow for missed and rescheduled sessions. Participants are encouraged to contact the counsellor or study staff to reschedule their appointments as needed. Participants receive session reminders via text message 24 hours and 15 min before each session.

Session documentation and fidelity

The counsellor completes session summary notes through a Qualtrics survey form, which includes closed-ended and multiple-choice questions such as session length, participant location, technical issues encountered, session topics selected, educational topics covered, goals set, a session content fidelity checklist and a narrative progress note.

Evaluation and curriculum modifications

The initial version of the Y2TEC intervention will be delivered to participants randomised to the intervention arm. The research team plans to adjust the intervention based on lessons learnt and feedback from participants to develop a modified version of the intervention (ie, intervention manual version 2.0). This version will be provided to all waitlist control participants, and outcome differences between the two arms will be explored during analysis. As a result, the intervention will have gone through an iterative refinement process and will be ready for implementation in a larger randomised controlled trial by the end of the pilot study.

Data collection and management procedure

Clinical data collection

At consent, participants sign a medical release form, and research staff obtain medical records from participants' respective medical clinics at baseline, 4 months and 8 months. Information collected includes appointment

Table 3 Measures in participant surveys

Domain (in order of the survey)	Measure	Baseline survey	Follow-up surveys
Demographics	Original measure	X	
Use of technology	Original measure	X	
HIV treatment outcomes, antiretroviral history and adherence	Original measure	X	X
HIV knowledge	HIV Treatment Knowledge Scale[34]	X	X
Alcohol use	Alcohol Use Disorders Identification Test[35]	X	X
Substance use	Alcohol, Smoking and Substance Involvement Screening Test [36] Q2 , Drug Abuse Screening Test-10[37]	X	X
Depression	Patient Health Questionnaire-9[38]	X	X
Adverse childhood experiences	Adverse Childhood Experience Questionnaire[39]	X	
Trauma/PTSD	PTSD Check List[40]	X	X
Anxiety	Generalised Anxiety Disorder-7[41]	X	X
Sleep	Pittsburgh Sleep Quality Index)[42]	X	X
Resilience	Connor-Davidson Resilience Scale[43]	X	X
Internalised HIV stigma	HIV Stigma Mechanisms[44]	X	X
Mental health and substance use stigma	SAMHSA Mental Health and Alcohol Abuse Stigma Assessment[45]	X	X
Social support	Medical Outcomes Study Social Support Scale[46]	X	X
Social isolation	Patient-Reported Outcomes Measurement Information System[47]		X
Healthcare empowerment	Healthcare Empowerment[48]	X	X
Relationship with healthcare provider	Healthcare Provider[49]	X	X
Unmet subsistence needs and instrumental support	Medical Outcomes Study Short Form[50]	X	X
Satisfaction and acceptability	Original measure		X

PTSD, posttraumatic stress disorder; SAMHSA, Substance Abuse and Mental Health Services Administration.

attendance, medications and laboratory data including plasma HIV RNA and CD4+ cell count. The data point closest to baseline, 4 months and 8 months ± 1 month are used for data analysis.

Assessment data collection

Participants complete assessment surveys at baseline, 4 months and 8 months after enrolment. The surveys collect demographic, technology use, substance use, mental health and HIV care information (see table 3). The baseline surveys are completed online in-person at the initial visit, and the other two are completed remotely on the participants' mobile devices.

Qualitative data collection

A subset of approximately 20 participants who have finished the intervention will be invited to complete an audio-recorded telephone semistructured individual qualitative exit interview with study staff for a $30 payment. Participants will be chosen to reflect a range of levels of engagement and attendance using a question adapted from the Session Rating Scale[27] to determine the level of satisfaction with each telehealth session. Using mean scores of participant satisfaction over 12 telehealth sessions and attendance, participants will be divided into four groups: (1) high attendance, high satisfaction; (2) high attendance, low satisfaction; (3) low attendance, high satisfaction; and (4) low attendance, low satisfaction. Five participants will be randomly selected from each category and interviewed. Participants will receive information and consent for the qualitative interviews during the initial visit, along with the consent for the rest of the study. The interviews will focus on the acceptability of the intervention and participant feedback on the intervention, and the interviews will be audio- recorded and transcribed verbatim.

Table 4 Primary outcome measures: feasibility and acceptability

Primary outcome measures	Metrics	Acceptance criteria
Acceptability	Measure participant satisfaction with the telehealth intervention at completion of intervention by a 30-item questionnaire (1 excellent to 6 unsatisfied) administered through an online survey	Mean satisfaction score≥80%
	Measure participant satisfaction with each telehealth session via 2-item scale (1 strongly agree to 4 strongly disagree) administered via text messaging	Mean satisfaction score≥80% over 12 telehealth sessions
Feasibility	Recruitment	At least 70% of the planned 80 participants (ie, n=56)
	Participant retention at 4 months	At least 80% of participants retained in the study at 4 months
	Participant retention at 8 months	At least 60% of participants retained in the study at 8 months
	Number of telehealth disconnections	Mean of one disconnection per videoconferencing session
	Participant response time to texts	Mean of 3 days between bidirectional text message and participants' response
	Sound quality based on a one item questions using Likert scale (0–10) (0=poor quality; 10=excellent quality) as rated by counsellor	Mean of 7 out of 10 sound quality
	Video quality based on a one item question using Likert scale (0–10) (0=poor quality; 10=excellent quality) as rated by counsellor	Mean of 7 out of 10 video quality

Confidentiality and data protection

All screening and consenting will take place in a private room. Study staff will use a secure, encrypted texting platform for all study text communication. Participants will receive support from study staff who will demonstrate how to set up additional privacy measures using the settings on their personal mobile telephones. Electronic data will be gathered through HIPAA-compliant platforms, stored on a secure network and password protected. Subjects will be coded by numbers and with no names; linking information will be kept in locked files. The data will not be shared unless via a data use agreement including deidentified data. The study has obtained a Certificate of Confidentiality from the National Institutes of Health to protect the privacy of potential and enrolled study participants.

Data monitoring

A Data Monitoring Committee (DMC), interim analyses and stopping guidelines are not needed because the study is a pilot feasibility study that has been classified as minimal risk by the UCSF IRB.

Study outcomes

Feasibility, acceptability and clinical outcomes

Preliminary data on feasibility, acceptability and HIV clinical outcomes will be gathered throughout the study (see tables 4 and 5). Acceptability of the telehealth intervention will be determined throughout the study using several methods. Study staff will administer two-session rating questions via text after each weekly telehealth session, asking if the participant 'felt heard, understood and respected by the counsellor' and if the 'session was right' for them. Additionally, a 30-item exit survey is administered through Qualtrics after the intervention is completed, including questions pertaining to (1) the overall rating of the study; (2) satisfaction with each study procedure; (3) ease or difficulty with each study procedures; (4) helpfulness of communication with study staff; (5) self-perception of improved ART adherence, mental health and substance use with study participation; (6) recommending a study similar to this to a friend; and (7) participating again in a similar study. Study staff will also conduct qualitative exit interviews with 20 participants to gather in-depth descriptions of participant experiences, perceptions and acceptability of the intervention. Clinical outcomes within the two study arms include HIV RNA, CD4+ cell count, self-reported adherence, appointment attendance, substance use (Drug Abuse Screening Test [DAST] and ASSIST) and mental health (PHQ-9 and PCL-5; see table 5).

Data analysis plan

Quantitative analysis plan

One-way frequency tables will be generated for all baseline and follow-up survey questions, and measures of central tendency and variability will be computed for continuous measures. Results from these analyses will

Table 5 Secondary outcome measures: clinical impact

Secondary outcome measures	Metrics
Alcohol use	Measure participants' alcohol use from baseline to 4 and 8 months using the Alcohol Use Disorder Test (AUDIT), a 10-item questionnaire to measure severity of participants' alcohol use. Responses are summed. Scoring range is 0–20+; 0–7: Low alcohol use, 8–19: Moderate alcohol use, 20+: High alcohol use/dependence.
Depression	Measure participants' depression from baseline to 4 and 8 months using the Patient Health Questionnaire 9, a 9-item Likert scale score (0–3) 0 ‘not at all’, 3 ‘nearly every day’. Responses are summed. Scores will have a range of 0–27. PHQ-9 scores of>10 are associated with moderate to severe depression.
Frequency of Substance Use	Measure participants' change in substance use from baseline to 4 and 8 months using a 10-item questionnaire (ASSIST) to measure frequency of participants' substance use.
Posttraumatic stress disorder (PTSD)	Measure participants' self-reported PTSD from baseline to 4 and 8 months using the PTSD Checklist—revised, a 20-item Likert questionnaire administered through an online survey. Scoring: 0 points for ‘not at all’, 1 point for ‘a little bit’, 2 points for ‘moderately’, 3 points for ‘quite a bit’, 4 points for ‘extremely’. Scores will have a range of 0–80. Responses are summed.
Self-reported medication adherence	Measure changes in participants' self-reported medication adherence based on 1-item adherence rating (1 excellent to 6 poor, lower rating indicates higher adherence) from baseline to 4 and 8 months.
Severity of substance use	Measure participants' changes in substance use from baseline to 4 and 8 months using the Drug Abuse Screening Test, a 10-item questionnaire to measure severity of participants' substance use. Responses are summed. Scoring (0–10); 0–2 low substance use, 9–10 severe substance use.
Measure of participant HIV knowledge using HIV Treatment Knowledge Scale	Assess participants' knowledge of HIV from baseline to 4 and 8 months through the HIV Treatment Knowledge measure, a 15-item self-report questionnaire. Scoring out of 15 (0–12 inadequate, and 13–15 adequate). Scores will have a range of 0–15.

ASSIST, Alcohol, Smoking and Substance Involvement Screening Test .

quantify important sample characteristics and participant use of various telehealth modalities as well as proportions and means of the feasibility and acceptability measures. Primary preliminary outcome analyses will use linear mixed models to compare mean log10 HIV RNA across the intervention and control groups at 4 months relative to baseline. Secondary exploratory preliminary outcome analyses will use the same analytic methods to compare the 8-month time point within the intervention arm to baseline to examine whether the intervention had longer-term effects. A parallel exploratory analysis will compare waitlist controls at 4 months versus 8 months.

Additional secondary exploratory analyses will repeat this set of analyses on other secondary outcomes such as CD4+ cell count, HIV knowledge, self-reported adherence and appointment attendance, PHQ-9 and PCL-5 mental health measures, AUDIT alcohol use measure and the DAST substance use measure. Finally, all analyses described above will be repeatedly stratified by participant gender to explore whether there is any evidence of gender differences in effects. Due to the modest sample size and pilot focus of the study, significance testing will be de-emphasised in favour of performing inferential analyses as a feasibility check to ensure all measures and analysis protocols are in place for a larger formal efficacy trial.[28 29]

Qualitative analysis plan

Study staff will complete, audio- record and transcribe individual in-depth interviews with 20 YLWH following completion of the clinical intervention. The analytic team will identify broad themes from the interview transcripts, discuss and refine them and then enter them into a Microsoft Excel–based matrix with a column for each theme and a row for each case. One coder will initially identify patterns in the themes and code each interview to identify subthemes, and a second coder will double code a random subsample (n=5) of the interview codes within the matrix. Discrepancies in coding will be discussed by the team until a consensus is reached and interrater reliability will be calculated. A sequential mixed-method design will be used to integrate our quantitative and qualitative data analysis.

Dissemination plan

Study staff will work with the UCSF Centre for AIDS Prevention Studies’ Community Engagement Core and the Youth Advisory Board to disseminate results to the community and participants via presentations, community forums, email updates and/or social media. Study staff will conduct town hall presentations and publish findings in peer-reviewed journals to communicate results with healthcare professionals.

DISCUSSION

This study protocol describes the Y2TEC pilot, randomised, cross-over study designed to impact the mental health, substance use and HIV care challenges of YLWH. Few interventions for YLWH currently exist that address these three concerns in an integrated way, and as a result, we had few examples of similar curricula while developing the Y2TEC intervention. Therefore, we relied on formative research including qualitative interviews with healthcare providers and staff serving YLWH, as well as a mixed-methods study examining HIV care engagement, mental health, substance use and technology-based interventions to address these issues with the target population [Saberi *et al*, under review,[15]].

Additionally, in our review of existing telehealth interventions focusing on these areas, we discovered that there were general telehealth guidelines but few specifics for research. For example, telehealth-specific regulations on best practices for responding to mental health crises described general practices for clinicians with little mention of best clinical practices for crisis response within a research setting.[30 31] We also found that there were few sources of information about best practices for using text messaging and telehealth counselling within research settings, as many healthcare providers who are currently holding telehealth appointments are practicing within medical groups that have officially adopted these technologies.[32]

This study has several unique aspects that are worth highlighting. This intervention explores non-traditional methods for care provision that deviate from the adult-care models and may be considered more 'youth friendly'.[33] The intervention was specifically designed to be tailored and adaptable to the participant using the results of the participant's assessment responses to inform the counsellor's decision-making around the number of educational and problem-solving sessions on particular topics. As a result, the counsellor is given the ability to spend more or less time on HIV care, mental health or substance use based on the acuity of the participant's need. Though this adaptive modular structure adds complexity, it has the potential to better meet the needs of participants than a more rigidly structured intervention.

Furthermore, this study simultaneously explores several unique aspects of feasibility and acceptability. In addition to exploring whether this form of intervention will impact HIV, mental health and substance use outcomes, we are also considering the acceptability of a fully online versus hybrid in-person online session delivery. Half of the participants receive the first intervention session with the counsellor in person and the rest of their sessions remotely, and the other half receive the full series remotely. If shown to be similarly acceptable, this intervention can be offered completely remotely.

The Y2TEC counselling series has been designed with replication and scalability in mind. The intervention is unique in the relatively low clinician time burden (6 hours of individual counselling per participant over 4 months) compared with traditional face-to-face counselling, which often involves weekly hour-long sessions (which may total 12–16 hours over 4 months). Additionally, if we find that participants perceive the remote-only counselling option as acceptable, implementing the intervention would require minimal office space and physical materials, limiting factors within healthcare settings. A remote-only counselling intervention would also potentially increase access for those living in rural areas with limited access to transportation or local services.

We anticipate that the findings of our study will show that a telehealth and text message–based counselling series for YLWH will be acceptable and feasible. We expect that the findings from this study will provide information about additional ways of using new mobile technologies to support the HIV care goals and behavioural health needs of YLWH and will help influence the development of additional mobile-based counselling strategies. The results of this pilot study will allow us to conduct a larger multicentre randomised controlled trial to examine the efficacy of this intervention.

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Contributors PS, CDR and MOJ conceived the study and developed the experimental design and measures. ARW and VAG developed the telehealth counselling intervention and manual. DAL and PS developed the main study protocols. ARW and DAL carried out the daily study activities. TBN contributed to the data collection and analysis plan. All authors were involved in the revision of the draft manuscript and have agreed to the final content.

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