ART of Conversation: Community Report

act

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TABLE OF CONTENTS

FORWARD

Maximizing the health and well-being of people living with HIV and preventing new infections depends largely on those with HIV being able to achieve and sustain a suppressed viral load. That means adhering to antiretroviral therapy (ART) - day in, day out - for a lifetime.

We know that adhering to ART is more difficult for people who have complex health needs - particularly those with complex mental health and substance use issues. The ART of Conversation - a collaborative, community-based research project between the AIDS Committee of Toronto (ACT) and Casey House - looked specifically at the potential of peers to empower and support people with HIV who have substance use issues as they make the transition from hospital to community.

One of the strengths of this project was that it looked beyond ART adherence to help participants set goals related to both their substance use and their personal lives. It recognized that, for someone struggling with addiction, personal goals such as a stable home and connections with family and friends are often more important than adherence and a critical part of the adherence journey.

From this project, we learned that people with complex needs highly value the connection with peers; we also learned that, for many marginalized people, there are barriers to phone support and that a weekly phone call may not be enough to meet their needs. Despite the problems that peers had reaching many of the participants by phone, they were highly effective in helping participants connect to their community and with programs and services offered by the ACT, such as support groups, the Buddy Program, women's programming, and counselling.

The ART of Conversation reinforces the importance of close collaboration between clinical and community-based services to empower and support people with HIV who have complex mental health and substance use issues. It highlights the value of peer-based programs as well as the need for more intense interventions that take into account the real-world challenges of people living with HIV and addictions.

We look forward to organizations like ACT and Casey House continuing to explore how best to support people making the transition from hospital to community in achieving not only their adherence goals, but also their personal and substance use goals.

Jean Bacon
Interim Executive Director
Ontario HIV Treatment Network (OHTN)

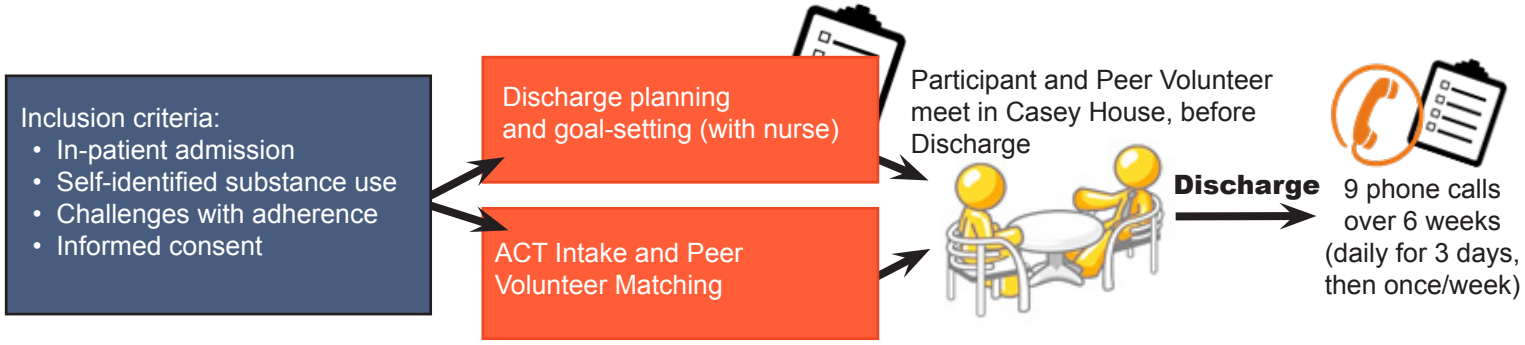
INTRODUCTION

Executive Summary

Hospital discharge can result in discontinuity of care, non-adherence to medications, and other negative outcomes[1], especially for people living with HIV[2,3] who face complex medical and psychosocial challenges[4]. 'Peer' programming (provided by trained community members who share lived experience with clients) may be a helpful and cost-effective complement to post-discharge support[5,6]. A pilot post-discharge peer program was conducted as a partnership between Casey House (Canada's only standalone HIV/AIDS hospital with 14 inpatient beds) and ACT – the AIDS Committee of Toronto (the city's largest community-based HIV organization). Seventeen people living with HIV consented to be matched with ACT Peer Volunteers during their transition from an inpatient admission at Casey House to community.

What is the *ART of Conversation?*

The ART of Conversation recruited 17 participants (people living with HIV who were inpatient at Casey House, experiencing medication adherence and substance use challenges, and would be discharged to community), for a 3-stage Peer-based intervention consisting of:



This study was designed using principles of Community-Based Participatory Research[7] (involving people living with HIV at all stages) and Minimally Disruptive Medicine[8] (planning a program that could fit into people's busy lives). The project was informed by Ontario's HIV/AIDS Strategy to 2026, specifically its call for coordinated care between clinical and community-based HIV organizations[9].

STUDY DESIGN

Overview

Following extensive consultation with people living with HIV, five Peer Volunteers were matched with seventeen Participants for post-discharge peer support during the period of April 1, 2017 to March 31, 2018. Data collection consisted of chart abstraction and demographic forms, and multiple interviews conducted by Peer Researchers. Data analysis was an iterative process involving a community-based team and focused on identifying what worked and what could be improved regarding the peer program.

Designing the *ART of Conversation*

This program was informed by consultation with people living with HIV in multiple forms. First, a community-based qualitative study that interviewed Casey House clients about the discharge transition found that participants were requesting support from a peer living with HIV[10]. Second, client engagement sessions were held with current and past Casey House clients about how they would like a post-discharge peer program to be structured, including: when the program starts and ends, what the peer support would be focused on, how to define 'peer', how the peers should be trained, and how the pilot program should be evaluated. Third, ACT volunteers who are living with HIV and who provide direct service through a Buddy Program and support group facilitation attended a group consultation. This consultation discussed what Casey House clients were requesting, how it could fit within ACT's model of volunteer service delivery, and whether attendees would like to engage with the project as a Peer Volunteer or Peer Researcher.

Based on our consultations with Casey House clients, for this project we defined **'peer'** as a person living with HIV who has personal or relational experience with substance use.

STUDY DESIGN

Preparing the Team

A team of people living with HIV, service providers (peer volunteers, social work, and nursing), and academics formed a community-based research team. Capacity-building activities were integrated into the project to support the meaningful collaboration of this diverse team. The team attended a 3-hour anti-oppression training facilitated by two ACT staff, and engaged in collaborative capacity-building throughout the project in topics such as data analysis. Peer Volunteers and Peer Researchers also participated in trainings for these roles.

Peer Volunteers

Five Peer Volunteers from ACT delivered this program. These volunteers attended ACT's Core Skills Volunteer Training, which is 22 hours focused on creating safe and accessible spaces, HIV and health promotion basics, concepts in communication, and anti-oppression & cultural competence. The volunteers then attended 22 hours of training specific to the ART of Conversation. This program-specific training, designed in partnership with the Ontario HIV & Substance Use Training Program, focused on harm reduction, structuring a call, communication tools, and self care. Peer Volunteers were compensated for their time.

Peer Researchers

Five Peer Researchers joined the research team as co-investigators prior to grant writing. They refined the questionnaires, collected all data, and participated in the analysis. The Peer Researchers attended an 11.5 hour training that was designed in partnership with Universities Without Walls. The training curriculum has been published in Action Learning: Research and Practice[11] - http://bit.ly/PR_Training. Peer Researchers were compensated.

The project was approved by the University of Toronto's HIV/AIDS Research Ethics Board (Protocol ID# 34124).

STUDY DESIGN

Objectives

1. To assess feasibility and acceptability of program components (setting goals, peer meeting, and post-discharge phone calls).

2. To connect people living with HIV who were in Casey House and experiencing medical complexity with ACT's programs and services.

Recruitment

A Casey House nurse approached people who were inpatient at Casey House, self-identified substance use and challenges with antiretroviral adherence.

Program Description

1. Goal Setting: Using motivational interviewing principles, a nurse worked with participants to set three discharge goals (ART adherence, substance use, personal goal), including identifying supports & challenges. These goals were shared with Peer Volunteers prior to them meeting Participants.

2. Peer Meeting: Peer Volunteers and Participants met at Casey House to discuss goals, upcoming discharge, & how phone support could be helpful.

3. Post-discharge phone calls: Peer Volunteers phoned Participants once/day for first three days, then once/week for following six weeks. Calls commonly lasted 20-45 minutes, focusing on goals and other issues.

STUDY DESIGN

Data Collection

Peer Researchers interviewed participants three times (following peer meeting, end-of-match, six-week follow-up) and interviewed volunteers twice per match (following peer meeting, end of match). Interviews were audio-recorded. Peer Volunteers completed a contact log of each phone call. Demographics were abstracted from participant charts and self-reported by volunteers.

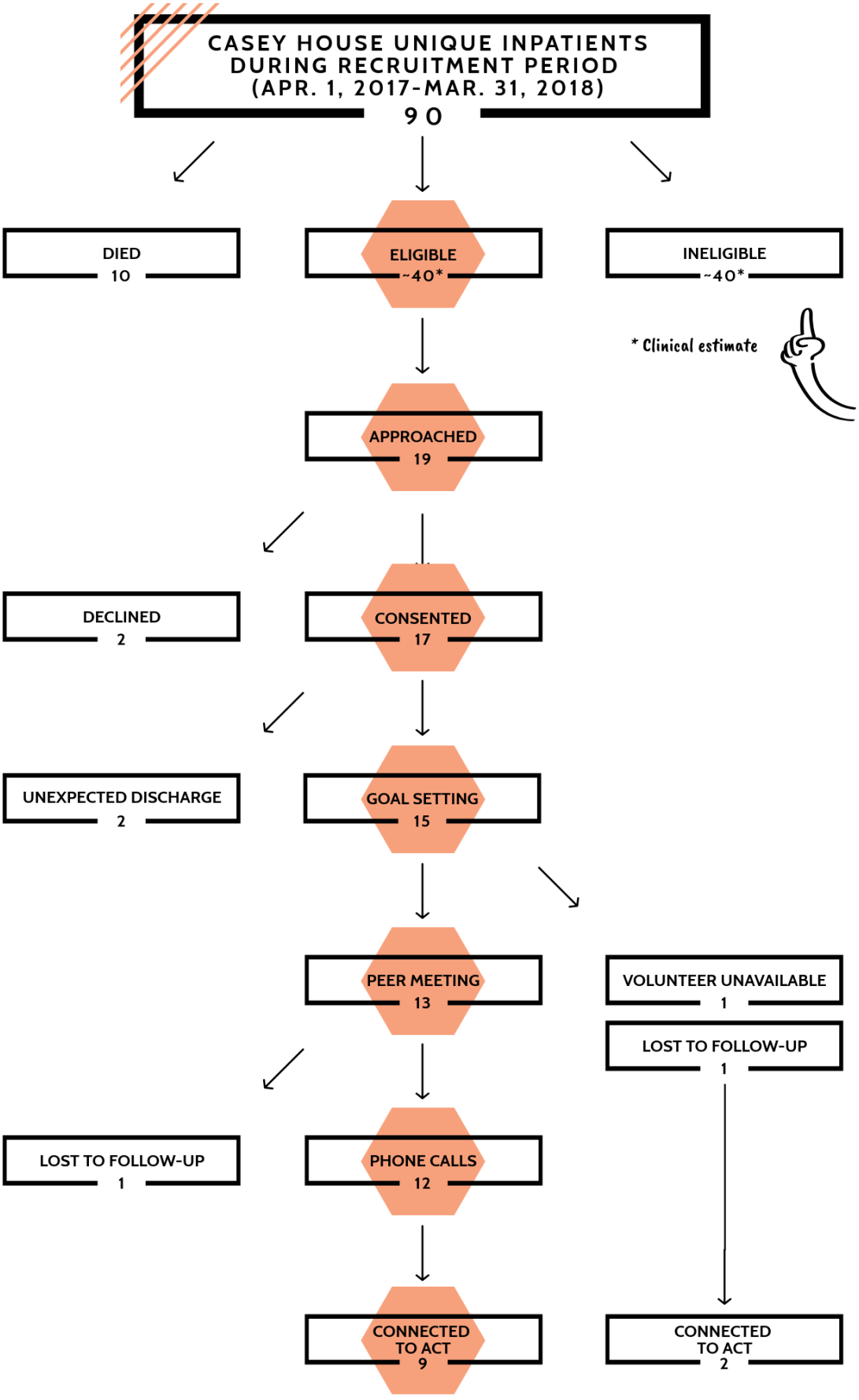
Data Analysis

Four research assistants transcribed interviews and entered data. The research team held three iterative analysis meetings to read through the data and discuss how the findings corresponded to the study's objectives.

RESULTS

The results section is organized into: participant flow chart, participant characteristics, setting goals, peer meetings, and post-discharge phone calls.

See next page for graph.


CASEY HOUSE UNIQUE INPATIENTS
DURING RECRUITMENT PERIOD
(APR. 1, 2017-MAR. 31, 2018)
90
DIED
10
ELIGIBLE
~40*
INELIGIBLE
~40*
* Clinical estimate
APPROACHED
19
DECLINED
2
CONSENTED
17
UNEXPECTED DISCHARGE
2
GOAL SETTING
15
PEER MEETING
13
VOLUNTEER UNAVAILABLE
1
LOST TO FOLLOW-UP
1
LOST TO FOLLOW-UP
1
PHONE CALLS
12
CONNECTED
TO ACT
9
CONNECTED
TO ACT
2

RESULTS

The majority of participants connected with programs and services at ACT (such as the Buddy Program, group programs, women's programming, and counselling). This connection was facilitated through the peer matching process and through the peer meeting and post-discharge phone calls.

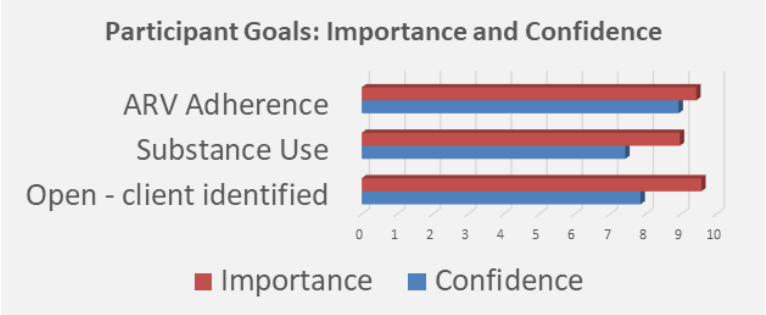
Here are demographics of the participants:

Participant Characteristics	N (%) / Mean (SD)
Gender	
Male	10 (59%)
Female	7 (41%)
Age (years)	49 (SD=11)
Comorbidities	
Mental health diagnoses	3 (SD=1)
Total comorbidities	8 (SD=3)
CD4 (N=14)	
>500	5 (36%)
200-500	4 (29%)
<200	5 (36%)
*Substances identified	
Crack cocaine	8 (47%)
Opioids	5 (29%)
Crystal meth	5 (29%)
*most common	

Setting Goals

Participants, with the support of a nurse, identified goals for after hospital discharge related to 1) their antiretroviral (ARV) adherence; 2) substance use; and 3) a personal goal. Participants rated their importance and confidence in achieving each goal. Most participants (15/17) set goals, the remaining two were discharged unexpectedly.

Participants self-rated importance and confidence regarding their goals are on the next page.



Participants expressed a high degree of confidence in achieving their ARV adherence goals, despite a reported history of challenges. Substance use goals were primarily abstinence-based and had the lowest confidence of success. Open-ended goals were the most important and primarily focused on improving living space and social connections.

These word clouds include all goals, as written:

Adherence

Substance Use

Open Client Identified

Peer Meeting

Peer Volunteers (living with HIV and have personal or relational substance use experience) were matched with participants and met in-person at Casey House prior to discharge to discuss goals, the discharge transition, and make a plan for post-discharge phone calls. This meeting usually occurred immediately after the participant set goals, so only one participant missed this meeting as they were lost to follow-up.

Quotes from Participants

“I wasn’t expecting somebody that young to be able to interact with me and understand me...I was even more comfortable when she told me she had HIV. And then I forgot all about [demographics], like we started talking you know She knows how to interact. It’s not a thing anybody can do. It’s not just about asking the questions it’s about making the person feel comfortable and she did that with me.” (Match 6 participant, female).
“He told me where he’s at…and I shared a bit, [I was] thinking this guy is going to be a counsellor…and then I realized, huh, this guy’s on my level” (Match 3 participant, male).

RESULTS

Quotes from Volunteers

"We went over his goals, kind of chatted about his life, his living situation when he gets out, kind of where his support systems are…he seems to want to have people around to talk so we really enjoyed chatting" (Match 7 volunteer, male).

"He was one of the founders of the program – he helped [design] the program at the beginning. So he kind of understood a lot of the stuff that was going on, so I didn't have to explain too much. We went through each of his goals, what they were, and he explained them to me, and he explained the bits and pieces I could help him with" (Match 8 volunteer, male).

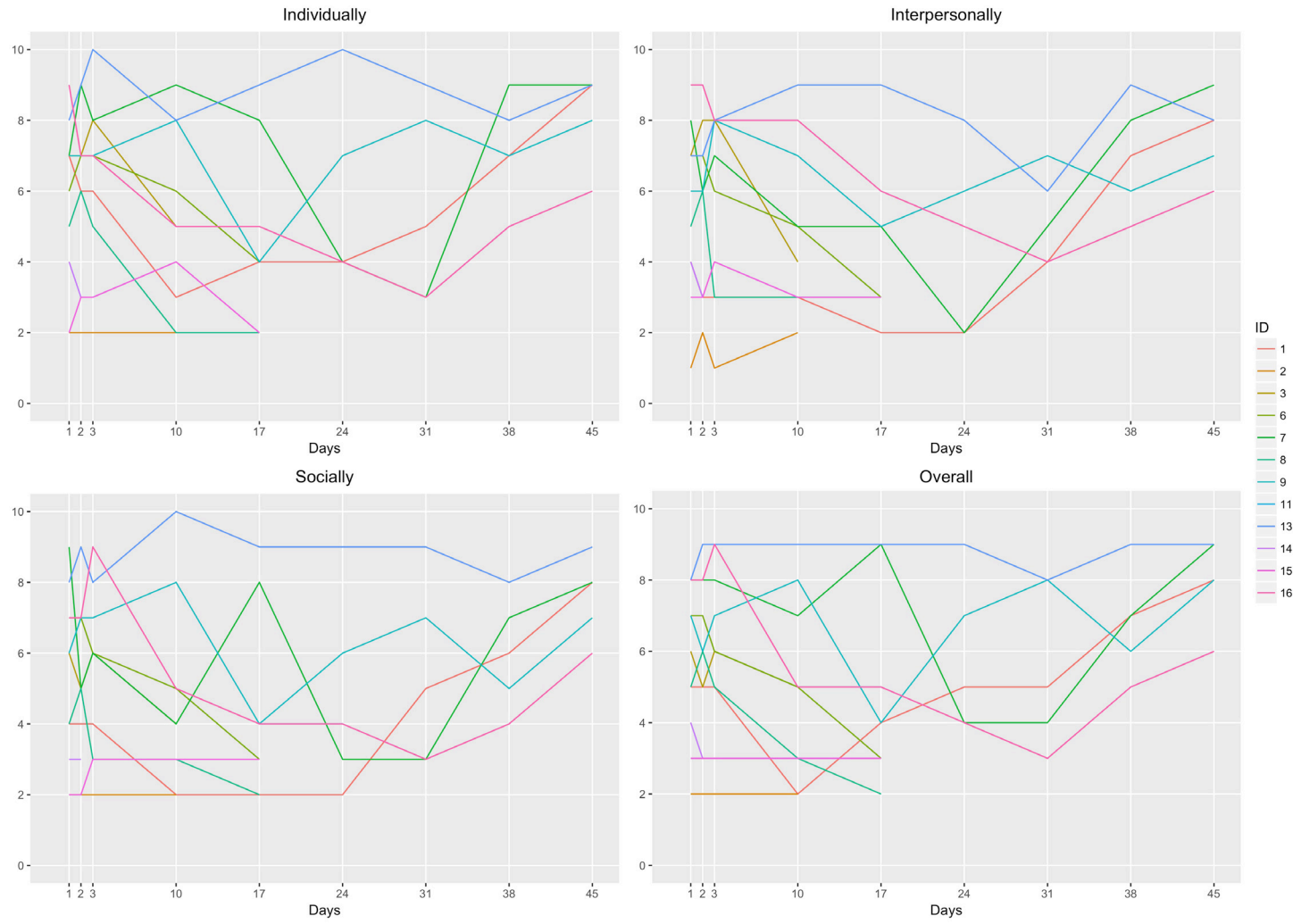
"She's super receptive and enthusiastic and seems to be really looking forward to the program…I was very well prepared, the [goal] sheet was thoroughly filled out… that amount of detail allowed the conversation to be more casual, we could talk about life and refer back to the goals as needed" (Match 13 volunteer, female).

Post-Discharge Phone Calls

Peer Volunteers phoned Participants once per day for the first three days, then once per week for the following six weeks. Calls commonly lasted 20-45 minutes and focused on goals and other issues. The phone calls were the most challenging component of this program, as half of the participants lost their phones, changed their numbers, and/or did not answer at some point over the six weeks of the program. Some participants appreciated the flexibility of phone calls and felt they could engage with a peer in this manner. Some participants indicated that the phone calls felt impersonal and that in-person peer support was preferable.

Peer Volunteers completed a log of each call. Logs included a Visual Analog Scale that rated how the participant was doing individually, socially, interpersonally, and overall from the volunteer's perspective, where 0 represents 'not well' and 10 represents 'excellent'. Overall, the most difficult period was 1-2 weeks post-discharge, with participants doing better by 5-6 weeks after leaving hospital. Participants who were lost to follow-up were rated as not doing as well as people who completed the program.

See next page for graph.



Post-Discharge Phone Calls

Quotes from Participants

"I'm just not a phone person…I don't know, I just can't. It's easier [in-person], you don't really know somebody [over the phone]" (Match 1 participant, female).

"The way we were able to interact, communicate, understand. It was like he understood everything I was saying and I understood everything he was saying. And it was great. I couldn't imagine not having someone like him. Yes, because it made me think, how do I explain it, in the last few years, I've been stuck in a hole. Like it just flew, no one to talk to, not one to help, nowhere to reach out, no nothing. When [Volunteer] came along it was like having a peer in a different type of background and culture" (Match 9 participant, male).

Quotes from Volunteers

“For lack of a better word, there was chemistry. There were a lot of shared circles and common experiences with regards to substance use, mental health, past relationships…so the impact on [Participant’s] goals, he looked forward to the calls and mentioned making progress each time” (Match 9 volunteer, male).

“He really seemed to look forward and appreciate the calls. I felt like I listened to him and helped in any way I could with resources. You can’t force people to do stuff, but I felt that if he needed help beyond the scope of what I could do, he had the resources” (Match 7 volunteer, male).

CONCLUSION

Feasibility and Acceptability

- Participants engaged with goal setting and peer meeting activities, and expressed appreciation for these program components.

- Targeted goal setting and peer engagement has the potential to ease the transition from hospital to community for some. However, significant barriers to service engagement exist post-discharge for people with complex medical and psychosocial conditions.

- There are many barriers to using telephone calls as a method of providing peer support with a marginalized population and for some may be too minimal of an intervention.

Connection to Community

- A majority of participants connected with programs and services at ACT following this program (such as support groups, Buddy Program, Women's programming, and counselling). This success of the peer program may help participants feel more connected to their community, and this may help with their overall health going forward.

- Through this project, Casey House and ACT pilot tested a model of peer support that fit within the frameworks of their hospital and community-based organization contexts.

Next Steps

- This partnership was an important step in Casey House's development of peer programming, with more to come in 2019.

AGENCY INFORMATION

ACT

Founded in 1983 by a group of community volunteers, today ACT is a leader in efforts to end AIDS in Toronto. Through HIV and sexual health education, support services, prevention and outreach, ACT is working towards a city with zero new HIV infections, zero HIV-related stigma and discrimination, and zero AIDS-related deaths. ACT's approach is guided by commitments to the Greater and Meaningful Engagement of People with HIV/AIDS (GEPA/MEPA), equity, self-determination, respect, and a strengths-based approach.

Casey House

Casey House is Canada's first and only stand-alone hospital for people living with HIV/AIDS, and provides inpatient, day health care and community programming, including outreach. Through their innovative and comprehensive approach to health care, they remain one of the few places where people with HIV/AIDS can seek care without judgment. After 30 years, Casey House is more than a place that saves lives, it is a place that speaks up, shines understanding through compassion, and empowers our clients to get better. Clients at Casey House feel respected and included.

Casey House's overarching approach to care is to ensure it's compassionate, it's personalized, uses a harm reduction philosophy and is always client-driven. In addition to providing excellent health care, Casey House is passionate about breaking down barriers and removing stigmas, as evidenced through their recent #smashstigma awareness campaign.

REFERENCES

1. Allaudeen, N., Vidyarthi, A., Masselli, J., & Auerback, A. (2011). Redefining readmission risk factors for general medicine patients. Journal of Hospital Medicine, 6(2), 54-60.

2. Kay, E. S., Batey, D. S., & Mugavero, M. J. (2016). The HIV treatment cascade and care continuum: Updates, goals, and recommendations for the future. AIDS Research and Therapy, 13(35), 1-7. doi:10.1186/s12981-016-0120-0

3. Kimmel, A. D., Martin, E. G., Galadima, H., Bono, R. E., Tehrani, A. B., Cyrus, J. W., & Krist, A.H. (2016). Clinical outcomes of HIV care delivery models in the US: A systematic review. AIDS Care, 28(10), 1215-1222. doi:10.13039/100000060

4. Schaink, A. K., Kuluski, K., Lyons, R. F., Fortin, M., Jadad, A. R., Upshur, R., & Wodchis, W. P. (2012). A scoping review and thematic classification of patient complexity: Offering a unifying framework. Journal of Comorbidity, 2, 1-9.

5. Genberg, B. L., Shangani, S., Sabatino, K., Rachlis, B., Wachira, J., Braitstein, P., & Operario, D. (2016). Improving engagement in the HIV care cascade: A systematic review of interventions involving people living with HIV/AIDS as peers. AIDS and Behavior, 20(10), 2452. ISSN:1090-7165

6. Simoni, J. M., Nelson, K. M., Franks, J. C., Yard, S. S., & Lehavot, K. (2011). Are peer interventions for HIV efficacious? A systematic review. AIDS and Behavior, 15(8), 1589-1595. ISSN:1090-7165

7. Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., … & Burris, A. (2011). Community-based participatory research: A capacity-building approach for policy advocacy aimed at eliminating health disparities. American Journal of Public Health, 100(11), 2094-2102. doi:10.2105/AJPH.2009.170506

8. May, C. (2009). We need minimally disruptive medicine. BMJ, 339(b2803). doi:10.1136/bmj.b2803

9. Bacon, J., & the Ontario Advisory Committee on HIV/AIDS. (2016). HIV/AIDS strategy to 2026: Focusing our efforts – changing the course of the HIV prevention, engagement and care cascade in Ontario. Ministry of Health and Long Term Care. http://www.health.gov.on.ca/en/pro/programs/hivaids/docs/oach_strategy_2026.pdf

10. Chan Carusone, S., O'Leary, B., McWatt, S., Stewart, A., Craig, S., & Brennan, D. J. (2017). The lived experience of the hospital discharge "plan": A longitudinal qualitative study of complex patients. Journal of Hospital Medicine, 12, 5-10.

11. Eaton, A. D., Ibáñez-Carrasco, F., Craig, S. L., Chan Carusone, S., Montess, M. Wells, G. A., & Ginocchio, G. F. (2018). A blended learning curriculum for training peer researchers to conduct community-based participatory research. Action Learning: Research and Practice, 15(2), 136-146. doi:10.1080/14767333.2018.1462143

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