ORIGINAL PAPER



Evaluation of Translife Care: An Intervention to Address Social Determinants of Engagement in HIV Care Among Transgender Women of Color

Lisa M. Kuhns^{1,2} · Anna L. Hotton³ · Judy Perloff⁴ · Josie Paul⁴ · Channyn Parker⁴ · Abigail L. Muldoon¹ · Amy K. Johnson^{1,2} · Robert Garofalo^{1,2}

Published online: 5 June 2019 © Springer Science+Business Media, LLC, part of Springer Nature 2019

Abstract

The TransLife Care (TLC) project was developed to address the structural factors that act as barriers to HIV care among transgender women of color. The purpose of this study was to evaluate the feasibility and initial efficacy of the TLC project; primary HIV care outcomes included linkage to HIV care, engagement in care, retention in care, use of ART and viral suppression among N = 120 participants. In multivariable analysis, receipt of the intervention (versus none), was associated with any HIV care visit (aOR 2.05; 95% CI 1.25–3.37; p=0.005), more total HIV care visits (aRR 1.45; 95% CI 1.09–1.94; p=0.011), being retained in care (aOR 1.58; 95% CI 1.03–2.44; p=0.038), and having a viral load test done (aOR 1.95; 95% CI 1.23–3.09; p=0.004). We conclude that a structural intervention, designed and delivered by the focus population, that directly addresses social determinants, is feasible and efficacious to promote HIV care engagement among transgender women of color.

Keywords HIV care engagement · Transgender women · Racial/ethnic minorities · Structural intervention

Resumen

El proyecto TransLife Care (TLC) se desarrolló para abordar los factores estructurales que actúan como barreras para la atención médica del VIH entre las mujeres transgénero de color. El propósito de este estudio fue evaluar la viabilidad y la eficacia inicial del proyecto TLC; los resultados primarios de la atención médica del VIH incluyeron el vínculo con la atención médica del VIH, la retención en la atención médica, el uso de ART y la supresión viral entre N=120 participantes. En el análisis multivariable, la recepción de la intervención (versus ninguna) se asoció con la participación en la atención médica (aOR 2.05, IC 95% 1.25–3.37, p=0.005), más visitas totales al VIH (aRR 1.45, IC 95% 1.09–1.94, p=0.011), se mantuvo en la atención médica (aOR 1.58; IC 95%: 1.03 - 2.44; p=0.038) y se realizó una prueba de carga viral (aOR 1.95; IC 95%: 1.23 - 3.09; p=0.004). Concluimos que una intervención estructural, diseñada y ejecutada por la población de enfoque, que aborda directamente los determinantes sociales, es factible y eficaz para promover el compromiso de la atención del VIH entre las mujeres transgénero de color.

Lisa M. Kuhns lkuhns@luriechildrens.org

- ¹ Division of Adolescent Medicine, Ann & Robert H. Lurie Children's Hospital, 225 E. Chicago Avenue, Box 161, Chicago, IL 60611, USA
- ² Department of Pediatrics, Feinberg School of Medicine, Northwestern University, Chicago, IL, USA
- ³ Department of Medicine, University of Chicago, Chicago, IL, USA
- ⁴ Chicago House and Social Service Agency, Chicago, USA

Introduction

The prevalence of HIV infection among transgender women is equal to or greater than among other traditionally high risk groups, such as men who have sex with men (MSM), with the highest rates among transgender women of color [1, 2]. A meta-analysis of the burden of HIV infection in transgender women found HIV prevalence in the United States (U.S.) was 21.7% (95% CI 18.4–25.1); transgender women had a 34-fold increased odds of HIV infection compared with all adults of reproductive age [1]. Among HIV-positive transgender

women, evidence suggests that social and economic factors are important determinants of health. Social determinants of health are the overlapping social structures, conditions, economic systems and circumstances that influence health and drive health inequities [3], including HIV-related outcomes [4, 5]. Among transgender women, social structures and conditions including discrimination, mistreatment, and adversity in the form of rejection from others can become a central part of their experience [6-11], affecting their ability to secure housing, employment, social services, and healthcare [6, 7, 12]. Furthermore, the legal problems encountered by transgender women may serve as barriers to HIV-related services and access to care [13]. An important goal of the U.S. National HIV/AIDS Strategy (NHAS) is that 90% of individuals in HIV medical care will be retained in care over time [14]. This poses a particular challenge for transgender women given multiple barriers to care and reduced likelihood of remaining in HIV primary care, once linked to care [15].

In recognition of these challenges, the Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau launched a Special Project of National Significance (SPNS) to evaluate innovative intervention services to identify, engage and retain transgender women of color in HIV care [16]. The TransLife Care (TLC) project of Chicago House and Social Service Agency was funded under this HRSA SPNS initiative to develop and test an intervention to intervene on the social and structural factors that act as barriers to HIV care among transgender women of color. The TLC is a "one stop shop" providing "bundled" housing, employment, legal, and outreach-based health services (i.e., triage, health education, and referral), in addition to HIV case management. The TLC intervention addresses the specific structural and social drivers of HIV risk among transgender women, drawing on a social determinants theoretical model of HIV risk. A key aspect of the TLC intervention is the transgender-specific nature of services (i.e., developed for and by transgender women), delivered by transgender staff, whenever possible. In addition, TLC services were provided to transgender women regardless of HIV status, although participation in the program evaluation, detailed herein, was restricted to HIV-positive participants.

The purpose of this study was to evaluate the feasibility and initial efficacy of the TLC project to promote engagement in HIV care among HIV-positive transgender women of color, through a prospective single arm trial carried out over a 24-month follow-up-month period.

Between December of 2013 and August of 2016, 122 par-

ticipants were enrolled in the TLC project in Chicago,

Methods

Study Sample

IL. Two participants were withdrawn from the study due to duplicate enrollment at another site, resulting in a final sample of N = 120. Participants were recruited via face-toface outreach to community-based organizations and institutions providing services to transgender women citywide (e.g., gender clinics, drop-in centers, shelters). Interested individuals were screened for eligibility, which included: (1) age 18 or older; (2) self-identify as transgender, transsexual, or female with a male biological or birth sex; (3) self-identify race/ethnicity as non-White; (4) HIV-positive (per self-report); (5) willing and able to provide informed consent. Exclusion criteria included: (1) unable to provide informed consent due to severe mental or physical illness, or substance intoxication at the time of interview or (2) enrollment at another HRSA SPNS site funded under this initiative (there were two Chicago-based sites; duplicates identified via name-based algorithm).

All participants were consented for participation. All study procedures were IRB approved. Upon enrollment, participants were able to engage in TLC services and continue to access services throughout the course of the project period (however, participation in this evaluation was not required to access TLC services; only data from those who consented to the evaluations are included herein).

Data Collection and Measures

At enrollment, participants completed a baseline questionnaire via computer-assisted self-interviewing (CASI), which included questions regarding participant sociodemographic characteristics and healthcare experiences (among other topics not included in this analysis). Participants completed the questionnaire again, in-person, at 6-month intervals until the end of the data collection period in August of 2017 (i.e., up to eight assessments over a 4-year period). Participants received \$25 for completion of the baseline assessment and \$50 for completion of each follow-up assessment. Completion of the study assessment at each data point took approximately 45-90 min. To document HIV care outcomes, medical records were abstracted from collaborating HIV care providers at 6-month intervals with a release of information from participants. Exposure to the intervention components was abstracted from TLC program records.

Primary Outcomes

Our primary HIV care outcomes included linkage to HIV care (any visit in the past 6 months or any history of ART use per medical record), engagement in care (any care visit over the past 6 months, total care visits over the past 6 months; visit types included the combined total of visits characterized as HIV care only, HIV and transgender care, transgender care only, or other), retention in care (≥ 2 care visits

in two consecutive 6-month periods with at least 60 days between visits; visit types included the combined total of visits characterized as HIV care only, HIV and transgender care, transgender care only, or other), current use of antiretroviral therapy (ART; past 6 months per medical record), viral load completed (completion of viral load noted in the medical record) and viral suppression (HIV RNA < 200 copies/mL based on past 6 month period).

Intervention Exposure

Intervention exposure was abstracted from TLC program records at 6 month intervals by type of intervention component (e.g., assistance with housing, employment, on-site medical care and education, legal services) and total hours of exposure across all intervention components for each period. We also calculated the cumulative number of hours of intervention exposure through the end of each 6 month period for descriptive purposes, but analyze intervention effects as time varying so that the timing of intervention receipt and study outcomes were more closely aligned.

Sociodemographic variables, including age (in years), race, ethnicity, gender identity, highest level of education, current employment, and income level were assessed using standard questions (for example, "What race do you consider yourself to be?"). We assessed prior homelessness and history of incarceration each with a single question ("Since the age of 16, how much time have you spent in a shelter for homeless people?" recoded to ever versus never) and history of jail/incarceration ("How many times have you been incarcerated in jail, prison, police lock-up or immigrant detention?" recoded to ever versus never).

Statistical Analysis

The primary analysis included all medical visits (i.e., HIV, transgender or other care); findings were similar when we restricted analyses to HIV-related visit types, which represented 93% of all medical visits and included HIV and combined HIV and transgender care visits. Although data were collected out to 36-months post-enrollment, significant reductions in sample size occurred after 24 months due to administrative censoring (i.e., the follow-up period ended for all participants in August of 2017, per the requirements of the funder); however, findings were similar when we restricted the follow-up period to 24 months (vs. 36 months), thus all follow-up analysis reflect a 24-month period. Intervention receipt was treated as a time-varying exposure in the primary analysis. We also conducted analyses examining dose of intervention as a time-varying exposure, which yielded findings consistent with the binary intervention analysis. Increasing hours of intervention exposure were associated with increased magnitude of association for each of the outcomes that were statistically significant, when the intervention was treated as a binary variable; however we present the simpler analyses here for ease of interpretation.

Post-enrollment differences in HIV outcomes by intervention exposure were assessed using logistic regression for binary outcomes (engagement, retention, ART use, viral suppression) and negative binomial regression for count outcomes (total HIV visits). Generalized estimating equations (GEE) with an exchangeable correlation structure were used to account for correlation among the repeated measures. Multivariable models adjusted for period, the baseline value of the outcome, and potential confounders based on a priori knowledge, including baseline age, race/ethnicity, unemployment, education, and history of homelessness. Overall trends over time were assessed by fitting GEE models with time as the primary explanatory variable. Analyses were conducted using SAS software version 9.4 (SAS Institute, Cary, NC).

Results

Participants (n = 120) were median age 27 (range 18–64); 94% were non-Hispanic Black (see Table 1). A total of 48.3% (57) received the any of the adjunctive services (i.e., housing, employment, legal, and outreach-based health services) within 24 months of enrollment (median interaction time = 9 h; Interquartile range (IQR) 1-66 h); the most commonly utilized intervention components were assistance with housing and medical care (see Table 2). Overall, the proportion who had any HIV care visit in the past 6 months declined from 60% at baseline to 41% at 24 months (p < 0.001); mean visits declined from 1.63 to 0.97 over this period (p < 0.001) (Table 3). Retention in care also declined, from 47% at 6 months to 35% at 24 months (p < 0.05). History of ART use (> 80%) and viral suppression remained fairly stable over the study period. In multivariable analysis, over 24 months of follow-up, receipt of any adjunctive service as a binary, time-varying exposure, was associated with engagement in care (aOR 2.05; 95% CI 1.25–3.37; p=0.005), more total HIV visits (aRR 1.45; 95% CI 1.09–1.94; p = 0.011), being retained in care (aOR 1.58; 95% CI 1.03–2.44; p = 0.038), and having a viral load test done (aOR 1.95; 95% CI 1.23-3.09; p = 0.004) (Table 4). However, engagement in care, total HIV visits, and retention in care declined over time overall, and the intervention was not associated with a statistically significant group difference in viral suppression among those with available viral load test results.

Table 1Baselinecharacteristics, TLCparticipants, N = 120

	n (%)
Age	
Mean (SD); range	30.6 (9.5); 18-64
Median (IQR)	27.4 (23.4–35.1)
Race/ethnicity	
Black NH	113 (94.2)
Latina	6 (5.0)
Other	1 (0.8)
Gender identity	
Female/woman	1 (0.8)
Transgender woman/transwoman/transfemale	111 (92.5)
Transsexual woman	3 (2.5)
Transgender	5 (4.2)
Education	
<hs< td=""><td>29 (24.2)</td></hs<>	29 (24.2)
HS or GED	73 (60.8)
>HS	18 (15.0)
Total household income, past 12 months	
<\$600	49 (42.2)
\$600-\$2999	38 (32.8)
\$3000-\$5999	11 (9.5)
≥\$6000	18 (15.5)
Ever homeless as adult $(N = 119)$	92 (77.3)
Ever incarcerated ($N = 102$)	50 (49.0)
Currently unemployed (N=116)	109 (94.0)
Time in years since HIV diagnosis (based on medical chart data; n=86)	
Mean (SD); range	5.8 (7.4); 0-32
Median (IQR)	3 (2–7)
Had any follow-up visit (after baseline, all visits)	81 (67.5)
Had first follow-up visit within 90 days of baseline	55 (45.8)
Time in days to first follow-up visit, Median (IQR); Range	49 (19–119); 2–336

 Table 2
 Distribution of total intervention exposure and specific components, TLC participants

	Baseline, n (%)	6 months, n (%)	12 months, n (%)	18 months, n (%)	24 months, n (%)	Total (cumula- tive exposure), n (%)
N	120	120	119	99	79	120
Intervention exposure						
Housing	23 (19.2)	25 (20.8)	13 (10.9)	15 (15.2)	7 (8.9)	46 (38.3)
Legal	9 (7.5)	8 (6.7)	3 (2.5)	2 (2.0)	2 (2.5)	18 (15.0)
Employment	6 (5.0)	8 (6.7)	4 (3.4)	2 (2.0)	1 (1.3)	18 (15.0)
Drop-in	5 (4.2)	9 (7.5)	7 (5.9)	11 (11.1)	7 (8.9)	30 (25.0)
Medical	20 (16.7)	27 (22.5)	13 (10.9)	21 (21.2)	11 (13.9)	53 (44.2)
Any intervention (in period)	27 (22.5)	33 (27.5)	19 (16.0)	22 (22.2)	12 (15.2)	-
Any intervention (cumulative) ^a	27 (22.5)	44 (36.7)	47 (39.5)	51 (51.5)	44 (55.7)	57 (47.5)
Total intervention hours in period, Median (min, max) ^b	3 (1–7.5)	6.0 (0.4–39)	6 (3–27)	3 (3–24)	6 (1–18)	9 (1-66)

^aCumulative intervention exposure through end of period

^bAmong those who received any intervention

 Table 3
 Trends over time in HIV continuum outcomes overall and by intervention exposure, TLC participants

	Baseline		6 months		12 months		18 months		24 months	
	N	N (%)	N	N (%)	N	N (%)	N	N (%)	N	N (%)
Any visit**	120	72 (60.0)	120	72 (60.0)	119	59 (49.6)	99	51 (51.5)	79	32 (40.5)
Intervention	27	16 (59.3)	44	29 (65.9)	47	22 (46.8)	51	29 (56.9)	44	21 (47.7)
No intervention	93	56 (60.2)	76	43 (56.6)	72	37 (51.4)	48	22 (45.8)	35	11 (31.4)
Total visits**, Mean (SD)	120	1.63 (2.04)	120	1.68 (2.28)	119	1.06 (1.67)	99	1.02 (1.37)	79	0.97 (1.74)
Intervention	27	1.63 (2.04)	44	2.43 (3.00)	47	1.09 (1.60)	51	1.24 (1.61)	44	1.36 (2.14)
No intervention	93	1.62 (2.05)	76	1.25 (1.59)	72	1.04 (1.72)	48	0.79 (1.03)	36	0.49 (0.85)
Linked to care**	120	79 (65.8)	120	87 (72.5)	119	90 (75.6)	99	75 (75.8)	79	57 (72.2)
Intervention	27	18 (66.7)	44	33 (75.0)	47	37 (78.7)	51	42 (82.4)	44	34 (77.3)
No intervention	93	61 (65.6)	76	54 (71.1)	72	53 (73.6)	48	33 (66.8)	35	23 (65.7)
Retained in care*	120	N/A	120	57 (47.5)	119	49 (41.2)	99	41 (41.4)	79	28 (35.4)
Intervention	27	N/A	44	22 (50.0)	47	21 (44.7)	51	22 (43.1)	44	18 (40.9)
No intervention	93	N/A	76	35 (46.1)	72	28 (38.9)	48	19 (39.6)	35	10 (28.6)
Current ART use	71	56 (78.9)	80	67 (83.8)	81	66 (81.5)	65	53 (81.5)	50	40 (80.0)
Intervention	15	12 (80.0)	30	24 (80.0)	35	28 (80.0)	36	32 (88.9)	32	26 (81.3)
No intervention	56	44 (78.6)	50	34 (86.0)	46	38 (82.6)	29	21 (72.4)	18	14 (77.8)
Viral load done*	120	60 (50.0)	120	53 (44.2)	119	48 (40.3)	99	49 (49.5)	79	29 (36.7)
Intervention	27	11(40.7)	44	22 (50.0)	47	18 (38.3)	51	27 (52.9)	44	20 (45.5)
No intervention	93	49 (52.7)	76	31 (40.8)	72	30 (41.7)	48	22 (45.8)	35	9 (25.7)
Viral suppression	60	46 (76.7)	53	40 (75.5)	48	37 (77.1)	49	38 (77.6)	29	24 (82.8)
Intervention	11	6 (54.6)	22	15 (68.2)	18	14 (77.8)	27	20 (74.1)	20	17 (85.0)
No intervention	49	40 (81.6)	31	25 (80.7)	30	23 (76.7)	22	18 (81.8)	9	7 (77.8)

Intervention = any intervention prior to and through the period (cumulative)

Baseline period = -6 months through enrollment date

**Trend test p<0.01; *trend test p<0.05

Table 4GEE models of TLCintervention effect on HIVcontinuum outcomes over24 months

Outcome 6–24 months	Time adjusted RR or OR (95% CI); p value	Multivariable adjusted RR or OR ^b (95% CI); p value		
Any visit	1.75 (1.23–2.49); 0.002	2.05 (1.25–3.37); 0.005		
Total visits	1.43 (1.07–1.93); 0.017	1.45 (1.09–1.94); 0.011		
Linked to care	1.07 (0.98–1.18); 0.141	Model did not converge		
Retained in care	1.51 (1.01–2.24); 0.044	1.58 (1.03–2.44); 0.038		
Current ART use	1.14 (0.86–1.51); 0.366	1.65 (0.74–3.67); 0.219		
Viral load done	1.84 (1.17–2.90); 0.009	1.95 (1.23-3.09); 0.004		
Viral suppression ^a	0.80 (0.39–1.64); 0.536	0.95 (0.45–2.03); 0.896		

Intervention effect modeled as a time-varying exposure

ART antiretroviral therapy, CI confidence interval, OR odds ratio, RR relative risk

^aAmong those with a viral load measurement available

^bMultivariable models adjust for time, baseline value of outcome, and baseline age, race, unemployment, educational attainment, and history of homelessness. Model for retention in care does not adjust for the baseline outcome value because retention in care was undefined for the baseline period. Effect estimates are presented as relative risks (RR) from negative binomial regression, and odds ratios (OR) from logistic regression

Discussion

Findings indicate both feasibility and initial efficacy for the TLC intervention to promote engagement in HIV care, retention in care and viral load assessment. Given the salience of social and structural barriers to HIV care among transgender women, our findings provide evidence for the success of this intervention approach to address those barriers using a bundled care approach. Given the reduction in engagement in care across time, however, we consider these findings incremental evidence of success; additional efforts are needed to build on these findings.

A key success of this intervention was engagement of a large number of HIV-positive transgender women, despite the TLC not being co-located with HIV care. This success may be attributable to the appeal of a social and structural intervention, which directly addresses the needs of the population. The sample for this evaluation exemplifies the need for these services with 77% having ever experienced homelessness, 94% unemployed and 49% with a history of incarceration. We found that the housing services and on-site, outreach-based, medical services were the most frequently accessed by participants. While the popularity of the housing services is not surprising, given the level of experiences of homelessness in the sample, the high level of participation in the health services was not anticipated, given the high level of engagement in HIV care at baseline. We partnered with a healthcare organization with many years of experience in outreach environments, with a keen desire to provide services to transgender women. Within the TLC drop-in center, participants could access these services without an appointment. This commitment to high quality, accessible, and competent service was very well received by program participants and was an entry point or re-entry point for HIV or gender care for some participants (via referral from the TLC).

Participants who received adjunctive services from the TLC intervention were more likely to engage in HIV care and to be retained in care over time. While all participants were exposed to the TLC assessment and referral program, only 48% engaged in any of the adjunctive services (i.e., housing, employment, legal, and health services). Findings suggest that additional uptake might have improved HIV outcomes further. It is not clear whether additional service uptake was not desired by participants or whether services did not meet their needs. For example, traditional employment services, including job readiness and placement services, may not have been viewed as specific enough to their needs given the potential of employment discrimination. Further research is needed to determine how participants perceive these services and how to modify them to best fit the needs of this population.

Finally, our analysis demonstrated a decrease in engagement and retention in HIV care over time. This trend demonstrates the potential intermittent nature of engagement in care in this population. Participants were engaged in HIV care with several different providers in Chicago (including three large providers) with varying levels of competence for transgender-specific care. While this project promoted competence among care providers via a parallel educational program offered to medical and social service providers [17], lack of transgender care or transgender friendly services may be one contributing factor to low engagement in care over time. These findings highlight the challenges to HIV care provision in this population. Research on longitudinal trends in service engagement and disengagement among HIV-positive transgender women and related intervention development is needed.

This study was limited by the relatively small sample size and missing data, particularly for visits beyond the 24-month follow up point. Although the TLC is not co-located with an HIV clinic, we offered incentives to the largest HIV service provider organizations to provide medical data for the majority of participants and tracked the data abstraction process very carefully (author AM) in order to avoid missing data. The study was not randomized, and there is potential for bias due to selective participation in the intervention or non-random loss to follow up. We controlled for potential confounders in the multivariable adjusted models, but there could have been differences on unmeasured factors. Missing data limited the number of covariates that could be included in the models as well as the use of more complex approaches, such as inverse probability weighting, to address these issues. Results should be interpreted in light of these limitations and replication in larger samples is needed.

Conclusions

We conclude that a community-based, transgender-specific, structural intervention that directly addresses the social determinants of HIV care among HIV-positive transgender women of color is feasible and may be an efficacious approach to promote HIV care engagement. Given the overall reduction in engagement in HIV care over time, we encourage continued work to develop strategies and intervention components to address these social and structure barriers and promote engagement in care in transgender women of color, building on our findings.

Acknowledgements We thank members of the TLC Team for their contribution to sample accrual and data collection. Thanks also to our community health partner, Heartland Alliance Health. Research reported in this publication was supported by Award Number H97HA24965 from the HRSA to Chicago House and Social Service

Agency. The content is solely the responsibility of the authors and does not necessarily represent the official views of HRSA.

Compliance with Ethical Standards

Conflict of interest No financial disclosures were reported by the authors of this paper.

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