

# Healthcare utilization, unmet service needs and linkage to care among people living with HIV/AIDS

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**Background:** Service utilization and service needs are key components of HIV care now that people living with HIV/AIDS (PLWHA) have a longer life expectancy and therefore develop more chronic diseases and related conditions. The purpose of this cross-sectional study was to investigate associations among PLWHA's service utilization, unmet service needs, and HIV treatment outcomes, as represented by linkage to care.

**Methods:** PLWHA (N=177) aged 18 years or older were recruited for a health service needs assessment project in Nevada between January and March 2016. Participants completed a self-administered paperpencil questionnaire in HIV clinics or completed the survey online. The purpose of the project was to identify utilization of medical services (e.g., medical care, specialty doctors, dental care) and support services (e.g., transportation, help filling out forms, child care) as well as unmet medical and support service needs with the goal of developing and implementing an Integrated HIV Prevention and Care Plan. The analyses included only the 165 participants who fully responded to the question about their linkage to care status. The independent variables were service utilization and unmet service needs. The dependent variable was linkage to care. Service utilization and unmet service needs included medical services and support services. Multivariable logistic regression analyses were conducted to examine associations between utilized services and unmet service needs with linkage to care. The most-cited problems during linkage to care were also reported.

**Results:** A majority (75.8%) of participants reported they were linked to care less than one month after receiving an HIV diagnosis. Service utilization and unmet service needs were not significantly associated with linkage to care (P>0.05). However, participants who reported late linkage to care also reported needing more help obtaining health insurance (P=0.03) and a greater need for support groups (P=0.048) compared to participants who reported a timely linkage to care.

**Conclusions:** More efforts must be taken toward providing needed services, such as psychological assistance, counseling and support groups to facilitate timely linkage to care. Appropriate measures of service utilization need to be developed and added to HIV care objectives.

**Keywords:** HIV; health services; linkage to care

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#### Introduction

Linkage to care is defined as the period from documented HIV diagnosis to visiting an HIV care provider or initiation of medical treatment (1,2). It is the starting point of engagement in HIV care for those who are newly diagnosed with HIV. In 2016, the recommended time for linkage to care was reduced to less than one month, in contrast to the previous 3-month recommendation in the United States (3). The goals of the U.S. National HIV/AIDS Strategy include increasing access to care and improving health outcomes for people living with HIV/AIDS (PLWHA) (4). The most recent (2020) objective for linkage to care is to have more than 85% of people who receive an HIV diagnosis linked to HIV care within one month (4).

Linkage to care, as an indicator of the HIV care continuum, is associated with a variety of other HIV outcomes. It reduces time to viral suppression (5). Early linkage to care is associated with early initiation of antiretroviral therapy (ART), which in turn is associated with reduced morbidity, mortality, and HIV transmission (6,7). However, current linkage to care rates are suboptimal in the U.S., with an estimated 78% or fewer PLWHA linked to care within one month of receiving an HIV diagnosis (1,2,8).

Linkage to care can be affected by the referral process and by follow up procedures and efforts of the healthcare system. Most healthcare providers and clinics create patient records during the first visit and also refer patients to sources of support for care, such as case management, financial support, and medical assistance (9). Linkage to care may share some structural-level factors with the patient's service utilization. For example, some structurallevel barriers could impede timely linkage to care (10). These barriers include health care system factors such as a lack patient navigation assistance and long appointment wait times, as well as social factors such as HIV stigma (10). These factors also have been identified as barriers to access to HIV healthcare services (11,12). Furthermore, interventions to improve linkage to care and HIV care utilization have used similar strategies, including health education, motivational counseling, and appointment assistance (e.g., peer accompany) and coordination (13).

HIV care has shifted to a chronic disease care model because PLWHA are living longer and are more likely to develop chronic diseases related to the HIV virus, HIV inflammation, and treatment (14). PLWHA might need various healthcare services and support services in addition

to HIV care. Therefore, service utilization becomes an essential component of HIV care for PLWHA if they are to potentially realize the most benefit from their HIV treatment. We are interested in the most commonly needed services, which were categorized into medical services (such as vision care, mental health care, and nutrition help) and support services (such as case management, transportation, and financial help). However, previous studies have focused on HIV-specific care rather than on more general healthcare services among PLWHA. For example, previous studies have established associations between HIV care and HIV treatment outcomes, such as ART adherence, viral suppression, and mortality (15-17). Very few studies have investigated service utilization in addition to HIV care.

Previous studies also have investigated individual healthcare services that are associated with linkage to care, such as care facility navigation and case management (10,18,19). One study included multiple types of service needs and found an association between service needs and medication adherence, which is one HIV treatment outcome (20). Previous studies have identified factors associated with linkage to care and service utilization (11,12); however, no studies have reported a direct association between linkage to care and service utilization. Moreover, previous studies that investigated service utilization did not distinguish between medical and support services (20), which are two different components in HIV care that might influence linkage to care differently. In this study, a wide range of healthcare services, medical services, and support services were included.

The study was conducted in the state of Nevada, which is located near the western coast of the U.S. Nevada has higher rates of HIV prevalence and new HIV diagnoses compared to the national level (21-23). These higher rates call for more attention to HIV prevention and care, which could effectively decrease new infections. Furthermore, most of Nevada's population is concentrated in three urban counties. The remaining 14 rural and frontier counties of Nevada comprise 87% of the state's land mass but only 9.7% of Nevada's population (24). The geographic distribution of Nevada's population is one challenge to delivering quality health care services, especially in rural communities.

Specifically, the hypotheses of the study are that: (I) medical and support service utilization will be positively associated with linkage to care; and (II) unmet medical and support service needs will be negatively associated with linkage to care. The results of the study could support efforts to leverage programming aimed to simultaneously improve

linkage to care and service utilization. The results could also be used to inform interventions designed to deliver needed services and to allocate health services to maximize the benefits of HIV care. We present the following article in accordance with the SURGE reporting checklist (available at http://dx.doi.org/10.21037/jphe-20-41).

#### **Methods**

# **Participants**

Participants (N=177) were involved in a Nevada health service needs assessment project. The purpose of the project was to identify HIV prevention and care service needs with the goal of developing and implementing an Integrated HIV Prevention and Care Plan. The project was conducted between January and March 2016. The study aimed to investigate the association of service utilization and linkage to care in the current HIV care model. The study population was PLWHA who were receiving HIV care. A cross-sectional survey study design was used to collect data regarding how participants were linked to care and their service utilization status.

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study used a de-identified secondary database from a needs assessment survey that was conducted for HIV prevention and care service program quality improvement purposes in which participants' consent were not required at the time of data collection. No personally identifiable information was collected in the needs assessment and participant consent was not required.

PLWHA were recruited from a variety of provider locations and community organizations through flyers, social media, and word of mouth during the study period. A letter was sent to HIV clinics, community organizations and the Department of Health and Human Services in Nevada to request assistance with recruiting participants for the survey. The letter also included a website link for participants to complete the online version of the survey. The inclusion criteria were being aged 18 years and older and currently living with HIV/AIDS. The convenience sample included newly diagnosed individuals, individuals who were retained in HIV care for a period of time, and Ryan White clients receiving HIV care. In addition, the analyses were limited to participants who answered the linkage to care question: "After you were diagnosed with HIV, how long did it take before you first saw a doctor?"

Respondents who did not answer this question (n=2) or who could not remember the length of time before being linked to care (n=10) were excluded from the study. The final analyses included 165 participants.

The survey was anonymous and took an average of 20 minutes to complete. Participants completed the self-administered questionnaire on paper in HIV clinics or online. The survey included questions that assessed sociodemographic factors, HIV disease status (the number of years HIV infected), service utilization, reasons for not getting services, linkage to care, reasons for late linkage to care, and medication adherence. All surveys and recruitment flyers were provided in English and Spanish. Participants received \$10 gift cards for their participation.

#### Measures

The needs assessment project began in April 2015 with meetings of stakeholders for HIV prevention and care in Nevada (including licensed medical providers, community health workers, specialists that are HIV focused, case managers, counselors, etc.). The statewide survey was developed and informed by two needs assessments and one regional study that were conducted in Las Vegas (25). Researchers and HIV medical professionals modified and finalized the survey based on the previous results (25).

The dependent variable was linkage to care, which was measured by the participants' response to the question: "After you were diagnosed with HIV, how long did it take before you first saw a doctor?" The survey provided seven response options, which were "I got into care immediately", "less than a month", "1-3 months", "4-6 months", "more than 6 months", "I have not seen a doctor since my diagnosis", and "do not remember". The variable was categorized into two levels based on the Centers for Disease Control and Prevention (CDC)'s criterion: timely linkage to care (participants were linked to care less than one month after receiving an HIV diagnosis) and late linkage to care (participants were linked to care more than one month after receiving an HIV diagnosis) (2).

The independent variables were service utilization and unmet service needs. The service utilization question asked participants to indicate all services they were using or had used in the current year (Appendix 1). The unmet service needs question asked participants to indicate all services that they needed but did not get. For both questions, participants chose from twenty-four services that were categorized into ten medical services and fourteen support

services. Examples of medical services were medical care, specialty doctors, and dental care. Examples of support services were transportation, help filling out forms, and child care. Service utilization and unmet service needs were coded as continuous variables.

The most-cited reasons for late linkage to care were reported. The survey included a list of twelve reasons for "What problems did you have getting into a doctor's office after your diagnosis?" The reasons were categorized into two groups: service reasons and other reasons. An example of a service reason was "The wait time was too long." An example of another reason was "I did not know where to go." Participants could select multiple reasons from the list.

Sociodemographic variables included age, gender, sexual orientation, and race/ethnicity. The number of years that a participant was HIV positive was also assessed.

# Statistical analyses

Chi-square tests, two-sample *t*-tests, and Fisher's exact tests were conducted to assess possible between-group differences (timely- or late-linkage to care) regarding sociodemographic characteristics, number of years of HIV infection, overall services utilization, overall unmet service needs, and individual service utilization and unmet service needs. Chi-square tests and Fisher's exact tests were conducted for the categorical variables and two-sample *t*-tests were conducted for the continuous variables. Multivariable logistic regression models were conducted to assess associations between service utilization, unmet service needs, and linkage to care.

Previous studies reported differences in linkage to care among different sociodemographic groups (19). Therefore, in order to eliminate the influence of sociodemographic characteristics, age, gender, and race/ethnicity were controlled in the model. The number of years of HIV infection also was controlled because research has shown that it has an indirect association with participants' service needs (26). Additionally, the most-cited problems that participants encountered during linkage to care stage were also reported. Analyses were performed using SAS 9.4 (Cary, NC).

# Results

# Sample characteristics

Approximately three-fourths (75.8%) of the participants reported they were linked to care less than one month

after receiving an HIV diagnosis (*Table 1*). There were no significant differences between participants who reported timely and late linkage to care with respect to age, gender, sexual orientation, race/ethnicity, and number of years of HIV infection. Timely and late linkage to care groups were not significantly different with respect to the number of medical (P=0.27) and support services (P=0.45) they utilized in the past year. The groups also were not significantly different regarding their unmet medical service needs (P=0.21) and unmet support service needs (P=0.73). However, the late linkage to care group reported needing more help obtaining health insurance compared to the timely linkage to care group (P=0.03). Additionally, the late linkage to care group reported a significantly greater need for a support group (P=0.048).

#### Service utilization and unmet service needs

In general, medical service utilization (means =2.4 and 2.8), support service utilization (means =2.6 and 2.9), unmet medical service needs (means =1.2 and 0.9), and unmet support service needs (means =0.7 and 0.8) were not high for the timely and late linkage to care groups (*Table 1*). As shown in *Table 2*, analyses indicated that participants' service utilization and unmet services needs were not significantly associated with timely linkage to care (P>0.05).

A majority (72.0%) of the participants reported that they had no problems linking to care (*Table 3*). The mostcited service reasons for late linkage to care were a long wait time and appointment-related issues. The most-cited other reasons for late linkage to care were a desire to avoid thinking about their HIV diagnosis, lack of information about where to go for care, and fear of disclosure of HIV status.

# **Discussion**

The purpose of this study was to investigate associations among PLWHA's service utilization, unmet service needs, and HIV treatment outcomes, as represented by linkage to care. The results showed that the participants' linkage to care was not significantly associated with service utilization and unmet service needs.

The results do not support the hypotheses that service utilization and unmet service needs would be associated with linkage to care. There are several possible explanations for this result. First, a standardized measure of service

Table 1 Participant (N=165) characteristics by linkage to care status

Characteristics	Timely linkage to care, <1 month (125, 75.8%)	Late linkage to care, >1 month (40, 24.2%)	P value
Age, continuous (mean, SD, years)	45 (12)	44 (13)	0.45 <sup>§</sup>
Gender			0.26*
Male	87 (73.7)	33 (82.5)	
Female	31 (26.3)	7 (17.5)	
Sexual orientation			0.44*
Heterosexual	36 (28.8)	11 (27.5)	
Homosexual	63 (50.4)	24 (60.0)	
Other	26 (20.8)	5 (12.5)	
Race/ethnicity			0.052#
White, not Hispanic	39 (31.5)	15 (38.5)	
Black, not Hispanic	38 (30.6)	7 (18.0)	
Hispanic	21 (16.9)	13 (33.3)	
Other/unknown	26 (21.0)	4 (10.3)	
Number of years HIV infected, continuous (mean, SD, years)	12 (11)	14 (11)	0.47§
Used services this year			
Medical services (mean, SD, range 0-10)	2.4 (2.0)	2.8 (1.7)	0.27§
Support services (mean, SD, range 0-14)	2.6 (2.2)	2.9 (2.5)	0.45§
Unmet service needs			
Medical services (mean, SD, range 0-10)	1.2 (1.8)	0.9 (1.1)	0.21§
Support services (mean, SD, range 0-14)	0.7 (1.3)	0.8 (1.3)	0.73§
Individual used services and unmet service needs			
Help getting insurance			0.03*
No	105 (85.4)	28 (70.0)	
Yes	18 (14.6)	12 (30.0)	
Need support groups			0.048*
No	118 (95.9)	34 (87.2)	
Yes	5 (4.1)	5 (12.8)	

SD, standard deviation. \*Results from Chi-square test; \*Results from Fisher exact test; \*Results from Two-sample t-test.

utilization and unmet service needs is not yet available in the research literature. Previous studies used individual services such as patient navigation assistance and case management (10,18,19). This study included a wide range of services in HIV care that were categorized into medical and support services. Research in this field would benefit if there were a universally accepted definition of services and a

standardized measure of service utilization. In addition, this study provided a method of measuring service utilization in HIV care as well as evidence in support of the establishment of a universal and more compelling measure.

Second, commonly used HIV indicators include ART adherence, linkage to care, and viral suppression. Service utilization is not a commonly assessed indicator of HIV

Table 2 Associations between used services, unmet service needs, and timely linkage to care

Overhan	Timely linkage to care			
Services	OR (95% CI)	AOR* (95% CI)	P value	
Used services				
Medical services	1.11 (0.92–1.33)	1.11 (0.89–1.38)	0.37	
Support services	1.06 (0.91–1.24)	1.11 (0.93–1.32)	0.27	
Unmet service needs				
Medical services	0.89 (0.69–1.14)	0.74 (0.52-1.04)	0.08	
Support services	1.05 (0.80–1.39)	0.84 (0.56–1.25)	0.39	

OR, odds ratio; AOR, adjusted odds ratio. \*Adjusted for age, gender, race/ethnicity, and number of years HIV infected.

Table 3 Participant reasons for late linkage to care

What problems did you have getting into a doctor's office after your diagnosis?	Frequency (%)	
I did not have any problem	118 (72.0)	
Service reason		
1. The wait time is too long	7 (4.3)	
2. I did not have a way to get to the appointment	4 (2.5)	
3. I could not get an appointment	3 (1.9)	
Other reason		
1. I did not want to think about having HIV	17 (10.5)	
2. I did not know where to go	15 (9.2)	
3. I did not want anyone to know I have HIV	13 (8.0)	

care and it typically is not a program objective (2). Service utilization is not included in national HIV/AIDS strategies that guide program priorities and actions (4). The absence of service utilization as an HIV indicator or as a focus of national HIV/AIDS strategies impedes funding for research and program efforts to further investigate and improve service utilization in an HIV care context.

In contrast, linkage to care, as a proxy indicator of HIV care (2), is a focus of national goals and it has a standardized measure recommended by the CDC (1). Programs and interventions with the aim of achieving the national goal of linkage to care have generated positive results (27,28). Timely linkage to care rates for PLWHA increased from an estimated 59% to 66% from 2009 to 2011 to 78% in 2017 (8,29-31), which is similar to the 75.8% rate found in this study. The comparably slow progress in recent years regarding measurement and goals of service utilization may be one reason for the nonsignificant association between

service utilization and linkage to care.

Third, service utilization covers all services in addition to HIV care in a health care context. Interventions with the goal of facilitating service utilization commonly focus on specific services (32,33). These efforts often face challenges. For example, integrating mental health care with HIV primary care requires multidisciplinary collaboration, administrative integration, and changes in referral procedures (34). Although some interventions showed effectiveness (35), unmet needs for ancillary services were still high (36,37). As a result, although linkage to care and service utilization share some common structural-level factors, such as clinic (e.g., care facility navigation and appointment waiting time) and provider factors (e.g., HIV stigma) (10,11,12), improvement in service utilization requires a sustained effort and long-term interventions.

Integrated HIV care, in which multiple services are available and provided on site with HIV specific care, is

the goal of future HIV care models (38). Studies show that integrated HIV care is associated with improved outcomes, such as an increased viral suppression rate, and an increased retention rate (38,39). Some services were highlighted in previous studies, such as mental health and substance abuse services, adherence counseling, and some support services, and attempts have been made to integrate them with HIV care (38,39). This study focused on a wide-range of services that are needed by PLWHA. The results of this study provide a unique contribution regarding specific needed services that could be integrated with HIV care as efforts to improve HIV care continues.

Fourth, PLWHA's service needs and service utilization might be influenced not only by structural-level factors, but also by individual-level factors, such as age, duration of HIV infection, and comorbidities (26,40). Although some individual factors were controlled in the current study, it is possible that other potential factors (e.g., comorbidities, disease progress) influenced any possible significant association between service utilization and linkage to care.

The results indicated that participants who reported late linkage to care needed more help obtaining health insurance compared to individuals who reported timely linkage to care. Also, participants who reported late linkage to care showed a higher need for support groups. Late linkage to care can result in adverse health outcomes, such as prolonged viral suppression (41), and reduced quality of life (42), which in turn have a negative impact on the individuals' ability to work and their income. Therefore, it is not surprising that participants who were linked to care late needed more assistance obtaining insurance as well as more emotional support.

Participants also reported factors other than service reasons for their late linkage to care. Previous studies found that many participants experienced psychological distress, depression, and anxiety at the time they received an HIV diagnosis (43-45). This study's results are consistent with previous research which found that newly diagnosed individuals experienced HIV disclosure anxiety (46) and that they moved through a psychological process which progressed from denial to acceptance (47). The results suggest that interventions that provide emotional support to newly diagnosed individuals also could help link them to care more quickly. Also, programs that provide information and resources (e.g., psychological assistance and counseling service), and that facilitate making appointments with HIV clinics, can help facilitate timely linkage to care.

The study had limitations. The cross-sectional study

design limits inference of casual relationships among the variables. Furthermore, the self-report survey methods might be susceptible to recall and social desirability bias, perhaps leading to underreporting of late linkage to care. Nonresponse bias could occur if participants who responded to the survey were different from those who did not respond to the survey. However, although it was a convenience sample of PLWHA living in Nevada, when the results were compared with the 2014 Nevada HIV/AIDS Surveillance data for PLWHA, the sample's distributions of age, gender, race/ethnicity, county of residence, and sexual orientation are consistent with the results of the surveillance data (25). Finally, the relatively small sample, particularly in the late linkage to care group, may have limited the study's statistical power to detect possible significant associations. However, this was a difficult-to-reach group. HIV patients' service utilization of a wide-range of services has rarely been presented in the literature. This study contributes valuable evidence to the HIV healthcare service utilization literature.

In conclusion, this study investigated relationships between a wide range of service utilization and individual services and linkage to care, which is one major indicator of the HIV care continuum. More efforts are needed to develop appropriate measures to quantify service utilization. Service utilization goals need to be added to HIV care objectives in order to gain more attention and funding for research.

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## **Footnote**

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are

appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study used a de-identified secondary database from a needs assessment survey that was conducted for HIV prevention and care service program quality improvement purposes in which participants' consent were not required at the time of data collection. No personally identifiable information was collected in the needs assessment and participant consent was not required.

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# **Appendix 1 Twenty-four services listed in the survey**

# Ten medical services:

- 1. Medical care
- 2. Dental care
- 3. Vision care
- 4. Mental health care
- 5. Specialty doctors
- 6. Therapy (occupational, speech, physical)
- 7. Nutrition help
- 8. Referrals to get other health care or services
- 9. Help getting off drugs or alcohol
- 10. Home healthcare

# Fourteen support services:

- 1. Help paying for medicines
- 2. Help understanding medicines and how to take them
- 3. Help getting food
- 4. Help getting health insurance
- 5. Financial help
- 6. Transportation
- 7. Interpretation or translation into my language
- 8. Child care
- 9. Help filling out forms
- 10. Case management
- 11. HIV and health classes
- 12. Free condoms
- 13. Legal help
- 14. Support groups