Cancer Screenings in LGBTQ+ Population: Evidence from the VUSNAPS Study, 2021-2022

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ABSTRACT

Background

Preventive healthcare screenings and tests aid the process of diagnosing and improving one's overall health by identifying a disease before symptoms are felt or seen by an individual. Within preventive healthcare, cancer screenings play a fundamental role as cancer remains one of the leading causes of death within the United States. Although cancer screenings aid in the process of treating cancer early, there are barriers to care that concern the population of LGBTQ+ individuals. The purpose of this honors thesis is to bring awareness to certain cancer screenings, like breast, cervical, and colorectal cancer, and the factors that may influence access to screenings and care, such as anti-LGBTQ+ policies and legislations, discrimination, access to LGBTQ-affirming healthcare providers, and etc. Furthermore, this paper will touch on how certain aspects of access to care facilitate older LGBTQ+ access and engagement in cancer screenings that are appropriate for their age and gender.

Methods

Quantitative data obtained from the Vanderbilt University Social Networks, Aging, and Policy Study (VUSNAPS), which identified information on relationships, aging, and health for LGBTQ+ individuals in the South, was used to find comparative data concerning access to preventative care tests or screenings as well as access to LGBTQ-affirming health care providers. The study was conducted on the LGBTQ+ population in order to better understand the relationships and to further gauge how crucial life events, such as marriage, jobs, retirement, illness, and relocation, can impact relationships in terms of physical and emotional support. The data was collected from April 2020 to September 2021 from participants who are within the age range of 50 to 76 from Alabama, Georgia, North Carolina, and Tennessee. These participants

were recruited through community outreach at LGBTQ+ organizations and events as well as through social media.

Results

      The results of this study using the Vanderbilt University Social Networks, Aging, and Policy Study (VUSNAPS) Wave 1 data demonstrate that compared to the participants reporting a usual source of the care that was not LGBTQ-affirming, participants with an LGBTQ+ affirming provider were more likely to have ever and recently engaged in preventive care. For the colorectal screening in lifetime, those who had access to an affirming provider were more likely ever to have a colorectal cancer screening (81.9% compared to the 73.8%). However, there were no observed significant differences between having an affirming provider in the timely and lifetime receipt of the Pap Smear for cervical cancer and the mammogram screenings for breast cancer amongst women and transgender women.

Conclusion/Implications

      It is important to determine these significant relationships as there is a lack of LGBTQ+ research that currently exists as well as a need for better education for LGBTQ+ medicine in order to address these health disparities that do exist as well as to improve the health outcomes of the aging LGBTQ+ population.

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INTRODUCTION

There is a critical lack of sexual orientation and gender identity data currently available within the United States. This is because the LGBTQ+ population remains an understudied and underserved population although 7.1% of U.S. adults identify as lesbian, gay, bisexual, and transgender (Jones, 2022). Recently from July to September of 2021, the United States Census Bureau conducted its first large real-time national data collection that also comprised the LGBTQ+ population. Although this is the right step in the direction in terms of expanding collection of data, further analysis can create a more balanced, representative data of gender and sexual minority individuals within the United States. This is important as increased information can aid in efforts in improving health outcomes for individuals in the LGBTQ+ population.

This accumulation of data can also provide greater knowledge and understanding of preventative measures, such as cancer screenings. Cancer screenings are a form of secondary prevention used to detect the presence of the disease before the symptoms develop, allowing for earlier access to treatment.

BACKGROUND

The "war on cancer" declared by President Nixon was initiated by the signing of the National Cancer Act of 1971, a federal law aimed to find a cure for cancer and to improve cancer research and care. Unfortunately, even in the present day, cancer continues to remain a major burden to society as the second leading cause of death worldwide, causing a total of nearly 10 million deaths in 2020 (World Health Organization, 2020). Within the United States, in particular, the American Cancer Society predicts an accumulation of 609,360 deaths and 1,918,030 new cancer cases in the year 2022 (Siegel et al., 2022).

Over the years, the prevalence of cancer has decreased through significant advancements made in cancer treatments like surgery, chemotherapy, radiation therapy, and immunotherapy, which are all of the available options after its detection. For certain cancers, it is possible to detect the cancer before any of the signs and symptoms appear; thus, the earlier that it is diagnosed, the earlier and easier treatment becomes. Within preventive healthcare, secondary prevention methods, such as screening tests, aim to detect and treat diseases before the progression of the disease worsens. These screening tests can examine for chronic diseases, such as HIV, as well as cancers like breast, cervical, lung, and colorectal cancer. In numerous literature, it has been demonstrated that preventative healthcare is useful in terms of increasing overall lifespan and livelihood. Although these preventive healthcare outcomes are studied in many populations, it is not as frequently researched within the elderly LGTBQ+ population. As cancer impacts so many individuals in the United States, this further emphasizes the importance of cancer screening examinations as they play a vital role in increasing cancer survivorship.

This paper will focus on the cancer screenings of breast, cervical, and colorectal cancer, which are recommended so that the premalignant disease is able to be detected early before the progression of the cancer spreads and symptoms begin to show or be felt. However, there are certain controversies regarding the frequency and age in which these cancer screenings are conducted as there is a lack of universal cancer screening guidelines, which can translate to differences in care depending on one's primary care provider. Additionally, there are other certain barriers to care, such as anti-LGBTQ policy and legislation, public attitudes, discrimination, and a lack of medical provider training that can lead to differences in care, including cancer screenings. Furthermore, depending on the frequency and age in which these

screening examinations take place, it is important to consider that there may be accrued stress levels due to false positive results, which can lead to a waste in time and resources.

Cancer Screening Guidelines According to the U.S. Preventive Services Task Force

There are varying cancer screening guidelines based on different organizations. The cancer screening guidelines for the United States Preventive Services Task Force, a group of volunteer experts in disease prevention that work towards improving health by presenting evidence-based recommendations for clinical preventive services, are as follows:

Breast Cancer

Women within the age range of 50 to 74 years old should receive biennial screening for mammograms. For women that are between the ages of 40 to 49, the decision to get screened for breast cancer should be an individual one. However, there are risks to getting screened earlier as there is a greater chance of overdiagnosis and overtreatment.

Cervical Cancer

Cervical cancer can be detected through the Papanicolaou (Pap) test, which collects cells in the cervix to check for any changes that may develop into cancer, and the human papillomavirus (HPV) test identifies the virus that can cause these changes. For women ages 21 to 65 years old, it is recommended by the USPSTF that cervical cytology, the Pap smear, should be performed alone every 3 years from ages 21 to 29. For those between 30 to 65 years, it is recommended that the Pap smear be done every 3 years, and a high-risk human papillomavirus (hrHPV) test be conducted every 5 years. Another viable option would be co-testing, which is a screening process that combines hrHPV testing with cervical cytology every 5 years.

Colorectal Cancer

For colorectal cancer, regular screening tests should begin when you are 45 years old and should continue until age 75 and these testings are recommended to be conducted every 5 to 10 years. These screening tests include stool tests, flexible sigmoidoscopy, colonoscopy, and CT colonography. If you have certain risk factors for colorectal cancer, it is recommended that you get tested earlier than 45.

Barriers to Cancer Screening

Although these recommendations can improve cancer survival, there is confusion within a patient level context, where physicians are, at times, unaware of the needs of their patients. This is further emphasized among LGBTQ+ individuals. This can be due to numerous factors, such as anti-LGBTQ+ policies and legislation, discrimination, and a lack of knowledge and trust in the physican-patient relationship, which will be further discussed in the latter paragraaphs.

Anti-LBGTQ Policy and Legislation

There are barriers that exist within legal and policy issues that can impact the LGBTQ+ community, which impacts health outcomes and within the healthcare system that can lead to a lack of access to preventive care and primary care providers due to factors, such as insurance complications, discrimination and a lack of cultural competency within healthcare providers and the healthcare system (Ward, 2014). Social determinants of health, such as economic stability, neighborhood and physical environment, education, community and social context, and the healthcare system, also play an influential role in impacting the health of LGBTQ+ individuals (Matthews et al., 2018). Negative marginality risk factors can also include an absence of a close network, low quality in relationships and feelings of isolation, which can impact both mental and physical health outcomes. In a study conducted in the Midwest (Minnesota, Iowa, and Wisconsin), it was revealed that amongst the individuals that were eligible for breast, cervical,

and colorectal cancer screenings, were less likely to receive preventive care due to the participants living in more rural areas of greater deprivation (Kurani et al., 2020).

Public Attitudes and Discrimination

Minority stress can contribute to these feelings as stigma, discrmination, and violence is very much present within the United States. Not only is this apparent in healthcare, but these are present in everyday life. Minority stress, or the chronic and cumulative stress to which individuals with stigmatized sexual minority identities are exposed, comprises experiences of discrimination, minority identity development, internalized homophobia, and concealment of one's sexual minority identity due to fear of judgment (Meyer, 2003). The minority stress model illustrates that the due to these encounters with stigma, prejudice, and discrimination, lesbian, gay, and bisexual individuals experience more stress than do heterosexuals, leading to poor heath, such as a greater likehood of mental and physical disorders.

The lack of information available concerning the LGBTQ+ population is correlated to how healthcare policy and law impact these populations. For example, according to the data provided by the National Health Interview Survey by the CDC in 2015, 83.3% of heterosexual women reported having completed a Pap test within the past 3 years; however, only 74.6% and 77.9% of lesbian and bisexual women reported the completion of a Pap smear. This aligns with information revealing that the lesbian and bisexual individuals are also less likely to receive preventative screenings, according to the CDC. This sheds light on how although these varieties of tests are available, access to preventative screenings, such as cancer screenings, can be dependent on numerous factors, such as health insurance, socioeconomic status, and LGBTQ+ status.

As mentioned earlier, the population of LGBTQ+ individuals face constant stressors due to experiences regarding discrimination. Although public perception is changing in comparison to the past, there still exists prejudice in various communities. In Lewis et al. (2017), a study was taken in order to observe public attitudes and the degrees of acceptance towards the LGBTQ+ community. It was revealed that Americans make distinctions between groups of gay and lesbian individuals versus transgender individuals, expressing more positive and "warmer" feelings and attitudes towards the population of gay and lesbian individuals in comparison to transgender people. Furthermore, they were also less likely to support discrimination protections for transgender persons. These are huge obstacles for LGBTQ+ rights activists, who are also supporting transgender rights, acting as a deterrent for many transgender individuals to receive care, such as cancer screenings.

Medical Provider Training/Compliance

A lack of competent and LGBTQ-affirming providers can lead to provider biases (Cahill 2018). Aspects, such as utilizing the correct pronouns and names with transgender patients, as well as collecting sexual orientation and gender identity data without any assuming, preconceived notions, can increase the likehood of preventive screenings as well as improve treatment outcomes. A systematic review of discrimination against LGBTQ+ individuals within healthcare settings also revealed that the knowledge and educational levels, beliefs, and religion displayed by the healthcare providered influenced their attitudes and treatment as well as their homophobia level (Ayhan et al., 2019). A lack of medical provider training and compliance can explain why transgender adults report having differing accesses to providers and healthcare, depending on the geographic region (Hughto et al., 2016).

METHODS

<u>Study Sample</u>

This paper utilizes the primary survey data (n=1,256) retrieved from Wave 1 of the Vanderbilt University Social Networks, Aging, and Policy Study (VUSNAPS), a cross-sectional study approved by the Vanderbilt University Institutional Review Board. VUSNAPS focuses on the relationships between health, aging and social networks in the LGBTQ+ population. Specifically, the survey was conducted in order to better understand the relationships of older lesbian, gay, bisexual, transgender, nonbinary, and gender nonconforming adults that live in the South and to further gauge how crucial life events, such as marriage, jobs, retirement, illness, and rellocation, can impact relationships in terms of physical and emotional support. The data from Wave 1 was collected from April 2020 to September 2021 from participants who were between the ages of 50 to 76 from Alabama, Georgia, North Carolina, and Tennessee. These participants were recruited through community outreach at LGBTQ+ organizations and events as well as through social media.

<u>Measures</u>

Access to LGBTQ-affirming healthcare provider

Participants were asked questions regarding their access to an LGBTQ+ affirming care provider. The question was "Do you have an LGBT-affirming healthcare provider?". Options were as followers: "Yes, they are my primary health care provider", "Yes, I see them in addition to another healthcare provider", "No, I don't need to want an LGBT-affirming healthcare provider", "No, I cannot find an LGBT-affirming healthcare provider in my area", "I don't know", and "No answer".

Preventative Care

Within the survey, participants were also asked questions regarding preventive care tests or screenings. The question was as follows: "Have you ever had any of the following preventative care tests or screenings: (check all that apply)". Participants had the option to choose from the following: (1) Flu shot, (2) Breast cancer screening or mammogram, (3) Pap smear or pap test, (4) Colorectal cancer screening or colonoscopy, (5) HIV test, and (6) I have never had any of these tests or screenings. If any of these preventive screenings were indicated, the participants were then asked to answer the question: "Have you had any of the following tests or screenings in the last 3 years?". The Pap smear, or pap test, and the breast cancer screening or mammogram question were asked for women and transgender women only.

Covariates

Participant age, race and ethnicity, gender identity (cisgender man, cisgender woman, transgender/nonbinary/gender nonconforming), education, household income, state of residency, and health insurance coverage were all controlled during the analysis of this data.

Statistical Analysis

All analysis was conducted using Stata v17. For the binary outcome variables, the adjusted risk ratios were calculated and estimated using modified Poisson models with robust error variance. This provides unbiased estimates that are easily interpreted when the outcomes are common. The adjusted models also controlled for age, race and ethnicity, education, household income, state of residency, and health insurance coverage.

RESULTS

Within the Vanderbilt University Social Networks, Aging, and Policy Study (VUSNAPS) Wave 1 data, 1,128 LGBTQ+ adults had a usual source of care, other than the emergency room. Within these survey participants, 63% of these participants stated that they had an LGBTQ+

affirming provider. Table 1 displays the full demographic characteristics of this sample by gender, race and ethnicity, education, family income, state of residency, health insurance and by whether or not the individuals reported having an affirming care provider. Individuals who had an LGBTQ+ provider were more likely to identify as cisgender men, transgender, or gender non-binary (66.9% vs. 55.2%, p<0.001), as white (88.7% vs. 83.8%,p=0.062), to have completed a college degree or higher (75.1% vs. 65.11%, p=0.001), to have a family income above $60,000 (66.9% vs. 54.9%, p<0.001), and to be living in North Carolina or Tennessee (63.2% vs. 54.7%, p=0.002). Health-related characteristics were also compared, where it was shown that individuals with an LGBTQ+ affirming provider were also more likely to have health insurance coverage (97.0% vs. 94.2%, p=0.019).

Table 2 shows the results of preventive care and aging outcomes. Compared to the participants that reported a usual source of care that was not affirming, survey participants that reported having an LGBTQ+ affirming provider were more likely to have ever and recently engaged in preventative care than those without a provider, which includes routine checkups, flu shots, colorectal cancer screenings, HIV tests, mammograms (breast cancer), and Pap smears (cervical cancer). Individuals that reported having an LGBTQ+ affirming provider were 4.5% (95% CI 1.7 to 7.4%, p<0.01) more likely to have had a routine checkup in the past year. Furthermore, 7.6% (95% CI 0.7 to 15.0%, p<0.05) were more likely to have ever had a colorectal cancer screening with an LGTBQ+ provider.

There were no significant differences in the timely and the lifetime receipt of a Pap smear and mammogram screenings among women and transgender women as a result of having an affirming care provider. However, taking a look at Figure 1 plots adjusted risk ratios of the preventive cancer screenings estimated utilizing the modified Poisson regression models, the

results were as follows, which was that those with access to a LGBTQ+ affirming provider were 5.1% and 0.2% more likely to receive a mammogram, timely and lifetime respectively.

DISCUSSION

The results of this study using VUSNAPS Wave I data reveal the importance of preventative care screenings in improving health outcomes. It also highlights the significance of having access to an LGBTQ+ affirming provider as those with an affirming provider were more likely to have health insurance coverage and more likely to receive a timely colorectal cancer screening. There were no differences found for cervical and breast cancer screenings. This is interesting as previous data has shown, populations of lesbian and bisexual individuals are less likely to receive preventative cancer screenings; however, the statistics accumulated within the VUSNAPS state otherwise. Further data collection and analysis of LGBTQ+ individuals identifying as women or transgender women in the South would be needed to study this effect further.

Moreover, the statistical analysis of the full demographics of the sample comparing those with and without access to an LGBTQ+ affirming provider reveals that education, race, ethnicity, higher education, and geographical region all play a huge impact on overall health and health outcomes. This is important as it displays how sociodemographic factors contribute to the current structural inequalities within the United States healthcare system that hinders access to healthcare. This further emphasizes the importance and need for LGBTQ+ affirming care providers, who have also received medical training and compliance, and greater awareness and knowledge of LGBTQ+ individuals within society as a whole.

CONCLUSION

The data presented within the Vanderbilt University Study exemplifies how information on the health and relationships within the LGTBQ+ remain not as heavily studied as other populations, emphasizing the need for further data collection and analysis. However, the VUSNAPS is a huge step forward in the right direction as it provides interesting comparisons between the full demographics of the Wave I sample and access to an LGBTQ+ affirming provider in relation to preventative screenings. Some possible reasons for the lack of significant relationships in the Pap smears and mammograms could be that the sample size was too small or that there is a relatively higher baseline rate of preventive cancer screenings for breast cancer and cervical cancer as compared to colorectal cancer as there are certain specified time points listed and recommended for these two cancers.

A possible future direction would be a study that also encompasses other states in the South (such as Arkansas, Florida, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Texas, Virginia, and West Virginia), as well as the MidWest. Data from the Williams Institute at the UCLA school of law states that 24 out of the 30 states where same-sex couples are raising children are actually in rural communities in the Midwest, South, as well as the mountain regions of America. Thus, it would be also interesting to observe and survey the impacts of other rural-urban differences as well in terms of access to LGBTQ-affirming services.

Overall, I think that the data from the study also demonstrates and emphasizes the need for better education for LGBTQ+ medicine in order to address these health disparities that do exist as well as to improve the health outcomes of the aging LGBTQ+ population. Barriers to care, such as public attitudes and perceptions, anti-LGBTQ+ policies and legislation, and a lack of medical provider training and compliance all play a significant role in the health outcomes of

LGBTQ+ persons.

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TABLES

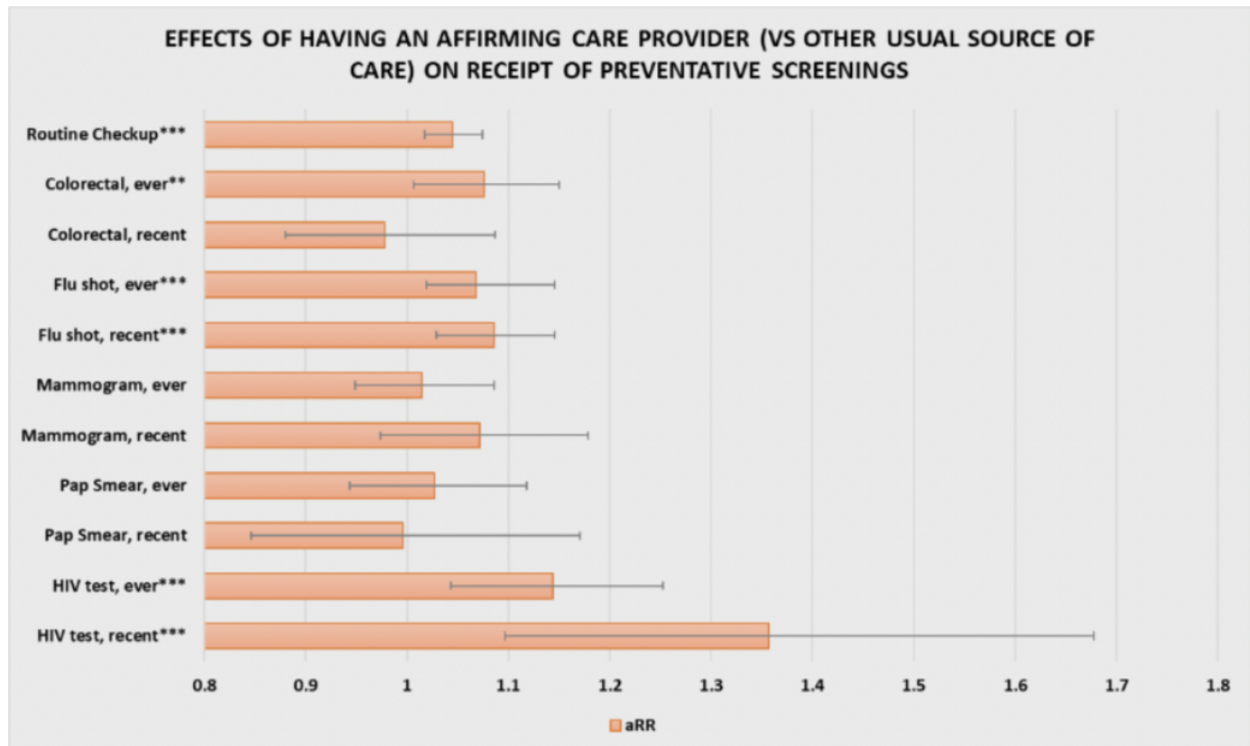| Table 1. Demographic Characteristics of the Sample					
	Access to LGBTQ+ Affirming Provider				
	No Access		Yes Access		
	No.	%	No.	%	p-value
Gender					<.001
Cis Man	211	51.1	406	57.3	
Cis Woman	185	44.8	234	33.1	
Trans/NB/GNC	17	4.1	68	9.6	
Total	413	100	708	100	
Race and Ethnicity					0.062
White	346	83.8	628	88.7	
Black	38	9.2	45	6.4	
Other POC	29	7	35	4.9	
Total	413	100	708	100	
Education					<.001
High school or less	26	6.3	26	3.7	
Some college, AA, Trade	110	26.6	140	19.8	
College degree	136	32.9	216	30.5	
Graduate/Professional degree	133	32.2	316	44.6	
Other educ	8	1.9	10	1.4	
Total	413	100	708	100	
Family Income					<.001
<35k	100	24.2	119	16.8	
35-45k	29	7	45	6.4	
45-60k	57	13.8	71	10	
60-75k	48	11.6	87	12.3	
75-100k	66	16	92	13	
100-125k	48	11.6	96	13.6	
125k+	65	15.7	198	28	
Total	413	100	708	100	
State of Residency					0.002
Alabama	94	22.8	108	15.3	
North Carolina	97	23.5	225	31.8	
Tennessee	129	31.2	222	31.4	
Georgia	93	22.5	153	21.6	

Total	413	100	708	100	
Health Insurance					0.019
No	24	5.8	21	3	
Yes	389	94.2	687	97	
Total	413	100	708	100	
HIV Status					<.001
Negative/Don't Know	397	96.1	591	83.5	
Positive	16	3.9	117	16.5	
Total	413	100	708	100	
Any Chronic Condition					0.051
None	62	15	78	11	
1 or more	351	85	630	89	
Total	413	100	708	100	
Data come from Wave I VUSNAPS (R01-AG063771)					

Table 2. Preventive Care, Chronic Disease Management, and Aging Outcomes by access to LGBTQ+ Affirming Provider							
	No Access		Yes Access		aRR	95% CI	Sample Size
	No	%	No	%			
Preventive Care							
Routine Checkup	387	93.7	695	98.2	1.045***	[1.017,1.074]	1121
Flu shot, lifetime	348	84.3	652	92.1	1.068***	[1.019,1.119]	1121
Flu shot, timely	329	79.7	632	89.3	1.086***	[1.029,1.146]	1121
Colorectal, lifetime	305	73.8	580	81.9	1.076**	[1.007,1.150]	1121
HIV test, lifetime#	155	73.1	289	80.7	1.144***	[1.043,1.253]	570
HIV test, recent#	80	37.7	166	46.4	1.357***	[1.097,1.678]	570
Mammogram, lifetime~	180	93.3	248	93.2	1.002	[0.952,1.054]	459
Mammogram, timely~	153	79.3	221	83.1	1.051	[0.961,1.150]	459
Pap Smear, lifetime~	171	88.6	229	86.1	0.972	[0.908,1.040]	459
Pap Smear, timely~	118	61.1	151	56.8	0.905	[0.773,1.059]	459
Chronic Disease Management							
Mental health condition under control	127	65.5	260	77.4	1.122*	[1.000,1.259]	530
Blood pressure under control	204	89.5	347	93.3	1.031	[0.976,1.089]	600
Diabetes under control	72	75	103	73	0.938	[0.805,1.093]	237
Heart condition under control	66	90.4	79	86.8	1.021	[0.917,1.138]	164
Respiratory condition under control	87	82.9	124	88.6	0.997	[0.897,1.108]	245
Arthritis/rheumatism under	69	50	100	50	0.922	[0.731,1.1	338

control						63]	
Aging Outcomes							
Level of Cognitive Decline	0	2	0	1	0.812*	[0.656,1.00]	1121
Impairments to Activities of Daily Living	0	1	0	1	0.896	[0.755,1.063]	1121

Data come from Wave I VUSNAPS (R01-AG063771) *p<0.1, ** p<0.05, *** p<0.01 aRR estimated via modified Poisson regression. All models adjusted for gender, race and ethnicity, age, educational attainment, state of residency, and health insurance status. # analysis conducted among pariticpants whose current gender identity is male, transgender/gender nonbinary. ~ analysis conducted among participants assigned female at birth. ^Summary statistics calculated via median and interquartile range, risk ratio calculated via Poisson regression with cognitive decline adjusted for current memory related diagnosis and ADL adjusted for having any chronic disease.

FIGURES

EFFECTS OF HAVING AN AFFIRMING CARE PROVIDER (VS OTHER USUAL SOURCE OF CARE) ON RECEIPT OF PREVENTATIVE SCREENINGS

Figure 1. *The Effects of Having An Affirming Care Provider (vs. Other Usual Source of Care) on*

Receipt of Preventative Screenings