UNIVERSITY OF DELAWARE
DISASTER RESEARCH CENTER

COVID-19: Impacts on Delawareans Living with HIV

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COVID-19: Impacts on Delawareans with HIV

In January and February 2021, researchers from the University of Delaware's Disaster Research Center (DRC) conducted a study of the impacts of COVID-19 on Delawareans living with HIV. When interviews began, over 60,000 Delawareans had tested positive for COVID-19 since the start of the pandemic, and over 1100 people had died from COVID-related causes. We know, however, that those numbers likely do not fully capture the extent to which COVID-19 spread throughout the state.

Although understanding the direct health risks to individuals with compromised immune systems is critical, this qualitative study examined the social and community impacts of the crisis. Our focus was on those Delawareans living with HIV in greatest need of economic and health care assistance: Those who qualify for benefits supported by the Ryan White Program.[1] The Delaware HIV Consortium (DHIVC) is one of seven Ryan White Program care providers, and many of their clients also simultaneously receive support services and case management from other Ryan White Program providers.

Drawing on a DHIVC client database, we spoke by Zoom/telephone with 55 people (approximately 12% of their DHIVC clients). These interviews lasted between 30-150 minutes, during which time participants discussed a broad range of issues and described in detail experiences since the pandemic began. This report highlights what they shared about the challenges they faced as well as the steps they took to meet those challenges.

COMMON CONCERNS

Many of the challenges and concerns of the people we spoke with mirrored those experienced by others across the country. Study participants worried for their young children or grandchildren who found it difficult to learn from home and fell behind compared to their academic achievements prior to the move to remote learning. They worried about others in their family, especially older parents. They were unable to attend the funerals of those close to them or see others at family celebrations and holiday gatherings, all of which they found incredibly difficult. They missed gathering with others at religious services, at cafes or backyard barbeques, and even by simply going shopping with a friend. They were frustrated with the time it took to receive testing results as well as the lack of clear information about vaccine eligibility in early 2021.

While some explained that their economic circumstances did not significantly decline in 2020, many others lost jobs, experienced lay-offs, or saw a reduction in employment hours. Strategies used to reduce risks included creating bubbles of close contacts, limiting or eliminating contact with others, donning items such as masks or gloves, cleaning surfaces, and staying at home. Participants in the study described challenges with depression as well as increased tension in their relationships. We highlight here several additional issues of concern for the Delawareans we spoke with who were living with HIV/AIDS as well as living through the global pandemic.

ECONOMIC IMPACT

Some people we spoke with indicated that their economic circumstances did not lead to many challenges. Approximately one-third indicated that their household income had increased since the start of the pandemic, although notably many in our study still did not have high levels of household income. For example, over 50% of the people we spoke with reported a 2019 household income of under $20,000. Some individuals opted to retire or leave their job when the pandemic struck, out of concern for COVID-19 exposure. In these cases, they expressed gratitude for their ability to do so.

Yet, many participants reported significant economic hardships. Sometimes these individuals noted they experienced precarious economic circumstances prior to 2020, and the fall-out of the pandemic set them even further behind. Several described how lay-offs, furloughs, or the closure of their place of employment left them searching for work at a time when jobs were scarce. At times, participants described poor communication from employers about when employees might expect to return to work. Others described how a reduction in hours led them to seek a second or third job to make ends meet. Their overall income remained the same, but only because of additional efforts and sometimes with assistance from family.

The need to spend additional funds on masks, gloves and cleaning supplies exacerbated economic hardships, as did spending on transportation once ride-sharing became risky. The economic instability described by some study participants included: needing to live with people who put them at risk; falling behind on rent and losing/almost losing a place to stay; losing access to transportation; and experiencing food insecurity. Several participants recalled how lack of grocery delivery, either from caseworkers or others in their network, posed problems early in the pandemic. One participant noted a lack of nearby food pantries. Several people described living in areas with high crime rates and in lodging that was in disrepair. We heard accounts of leases ending during the pandemic, requiring housing searches at a difficult time. Eleven percent of people we spoke with had moved in with others because of financial problems since the pandemic began. A few people navigated homelessness at some point during the pandemic, a situation made more difficult with the pandemic-related closure of libraries (where they might have otherwise accessed computers to look for work) or other establishments that might have mitigated the challenges associated with homelessness. Study participants who applied for financial assistance sometimes believed processes were delayed because of the pandemic.

Support to participants made a difference. Housing vouchers and utility payments they received through local organizations played an important role - sometimes cited as critical in enabling them to have housing security or subsidize the cost of expensive HIV medication. Participants credited both Housing Opportunities for Persons with AIDS and the Ryan White Program for this assistance. Unfortunately, these did not always sufficiently solve the challenges everyone faced. Additional support that proved helpful during the pandemic included others supplying food; receiving extra food stamps from the state, and others providing rides to grocery stores or COVID testing. Many people we talked with stated, however, they did not want to be a burden to loved ones.

> *“Everything since March 15 has been turned upside down…[various jobs are a] stop-gap to [a] slow leaking hole in the boat.”*

COVID-19 and HIV

TRUSTED SOURCES ON COVID-19

Participants frequently disclosed dissatisfaction with federal leadership regarding information and actions around the pandemic throughout 2020. Although they sought information from media news outlets, equally important were local leaders – such as the state Governor, religious leaders, and local agencies. Many people noted high levels of trust in their physicians or nurses (with whom they frequently interacted) and Anthony Fauci (with some participants referencing Fauci's career-long research on HIV/AIDS). Several participants specifically mentioned their caseworkers as trusted sources.

PROTECTIVE ACTIONS

We did interview some people who disregarded recommended protections. They described visiting indoors with people from outside their households or frequently attending larger gatherings. One noted: "Everything they were telling me to do, I would do the opposite." This was quite unusual, however, compared with most people we spoke with.

By and large, study participants were extremely concerned about contracting COVID-19. During 2020, they avoided going out, and limited/entirely avoided contact with outside their household. They reported strictly following recommended guidelines throughout the year. If they did leave home, they took protective action measures. Examples of such measures included: timing visits to the grocery store to avoid crowds; wearing masks; wiping down purchases; securing rides with others for COVID-19 testing or medical visits instead of using public transportation; avoiding dating; or not attending in-person religious services. Several explained how they carried extra supplies with them wherever they went. Others brought their own cleaning supplies to wipe down grocery carts because they did not trust others to do it properly. Many participants greatly appreciated the packages of masks, gloves, cleaning products, and hand sanitizer they received from case management organizations such as DHIVC, as well as religious and community organizations, indicating these were essential in helping them stay COVID-free. One person even noted they shared masks with others in their household prior to the arrival of DHIVC supplies, illustrating the necessity of such agency support in limiting the spread of the virus.

Overall, many participants were very conscious about living with one virus – HIV – and how contracting COVID-19 might negatively impact their health. That said, some study participants experienced high levels of exposure to others that were beyond their control. Examples included: living with non-family roommates or in households with many family members who did not always follow health recommendations; working in locations that frequently exposed them to the public or many co-workers; and having insufficient resources for masks or cleaning supplies.

PROTECTIVE ACTION, HIV/AIDS AND COVID-19

Repeatedly, the people we spoke with took the virus seriously. Many made a very explicit connection between the HIV/AIDS epidemic and the current COVID-19 pandemic. One person we spoke with was diagnosed with HIV in the 1980s. They related the feelings of hopelessness, helplessness, uncertainty, and struggles with seeing those close to them die at that time with the feelings permeating around COVID-19. This same person noted similarities between HIV and COVID-19 with respect to the spread of misinformation and misconceptions.

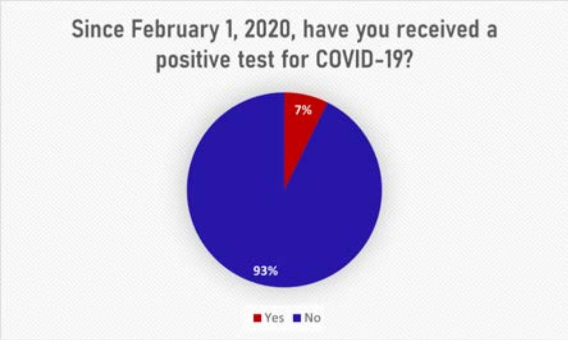
COVID-19 and HIV

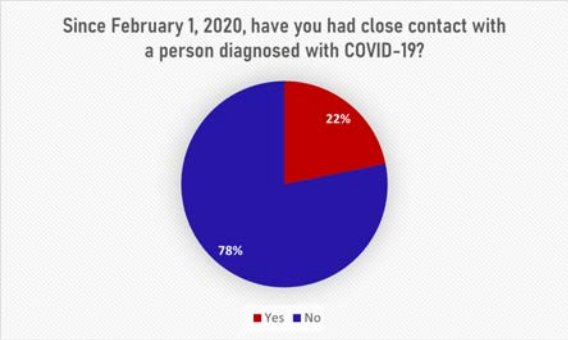
Interestingly, numerous people suggested that the strategies they used to manage HIV are comparable to those that governed their approach to COVID-19. These strategies included practicing discipline and avoiding situations that put one's health at risk. For example, one person stated the approach was simply "wear a mask" versus "wear a condom." Another said when stressing the need to wear a mask and to social distance: "It's just like, now, in this day and age, if you go out and have sex, you know to have a condom. This right here, this pandemic, you have to know common sense; you have to know what to do and what not to do." Conversation with participants suggested that many, particularly those who lived years with HIV, were primed to follow protective actions carefully and take the virus seriously.

> *"It's a sacrifice worth taking [taking protective measures and isolating] because I'm looking at the light at the end of the tunnel. I'm looking at the end of the road. And I would rather be here and healthy, than not ."*

PHYSICAL HEALTH

For some study participants, the pandemic provided an opportunity to improve their eating habits while avoiding fast-food dining, or they reported no change in their overall health. Yet, poor or declining health circumstances were noted by many other people we interviewed. Participants provided examples of physical health challenges, including seeking treatment for or recovering from cancer, suffering from chronic breathing difficulties, and experiencing accidental injuries from falls. Many people we spoke with noted a reduction in exercise or physical activity and the development of poor eating habits. Some struggled with maintaining sobriety, a healthy weight, or a healthy sleep schedule. Several study participants cited surgery delays, either because doctors classified their surgeries as elective or because the client postponed surgery for fear of contracting COVID-19 during hospital admission.





Seven percent of those interviewed reported receiving a positive COVID-19 test, although several others described being very sick in 2020 with what they suspected could have been COVID-19. Notably, however, this rate was near the 8% rate in Delaware at the time.[2] Twenty-two percent said they had direct contact with someone who tested positive for COVID-19. Many more reported knowing (but not having contact with) friends and family who contracted the virus, often saying they knew multiple people who had fallen ill. Study participants also said they knew multiple people who died from COVID-19. It was very clear that COVID-19 had a widespread impact on the health of those they knew quite well.

COVID-19 and HIV

Seventy-one percent of study participants reported having a virtual visit (using a smartphone or a computer) with a medical professional. Assessment was mixed regarding the success this form of communication had on meeting their health care needs. Some individuals noted that while they preferred in-person visits, the virtual visits met their needs given other constraints during the pandemic. Several study participants much preferred virtual visits, as it reduced the time and financial cost they would have normally invested in scheduling time off work, traveling to and from appointments, or waiting in a waiting room. At least one individual described feeling more comfortable having virtual visits, given other mental health considerations they were experiencing.

In contrast, other participants felt it was difficult to connect with a new doctor if meeting them for the first time through virtual visits. Moreover, some participants believed they were unable to communicate well when not in person. Some participants questioned whether their doctor could give an accurate assessment of their health (e.g. check their weight, for dehydration, or for gland swelling) or shared that it felt as though they ended up diagnosing themselves during those visits. As this respondent stated, which was echoed by a few others: “I don’t like virtual visits. I don’t think they can adequately do what hands-on can do….If I tell you [that] I am fine and I really am not, how would you know any different if you can’t see me?” Several participants noted they had difficulty using the web-based applications that were meant to connect them virtually with medical or social service groups. In short, clients were quite split regarding their experiences with this new way of connecting with their doctors, with some finding it preferable, some satisfied for now given the pandemic constraints, and others dissatisfied with the experience.

Several participants had rescheduled medical appointments because they could not afford to take time off from work during the pandemic. However, we heard numerous accounts of people avoiding medical care for fear of contracting COVID-19. These included: avoiding the hospital when ill (e.g. when suffering from a kidney stone); canceling dentist (most common) and eye appointments; and rescheduling other routine appointments (e.g. mammograms, podiatry, pain management). One person we interviewed nearly avoided seeking care at a hospital given concerns about COVID-19, but friends or family eventually convinced them to go. They were grateful for finally going to the hospital because the visit resulted in a cancer diagnosis for which additional care was sought.

> *“Nothing anybody can do but keep their distance from me. Respect my right to health.”*

Thirteen percent of the people we spoke with reported missing medication doses (including those for HIV) and 20% reported missing or delaying routine HIV lab tests during the pandemic. Contributing factors included lack of transportation; scheduling delays; not receiving prescriptions for tests or medication from doctors; changes in processes and insurance; and delays in time to refill medications.

> *“It’s very scary….you know because people [are] dying. You know, and I had a fight with HIV before and AIDS. I didn’t want to have that. I didn’t know if I would be able to have that fight in me again. That was [many] years ago. I had to fight. I didn't know if I had to fight this battle [with COVID-19].”*

COVID-19 and HIV

> *"The isolation of [the pandemic] is really what has affected me most... I contracted HIV [many years ago]...I am healthy and all that, but even today, having HIV is like having an albatross around your neck. I just kind of feel its hard to make friends or have intimacy with other people due to that. I feel there is still a big stigma out there concerning that."*

MENTAL HEALTH

Many participants described the emotional toll they experienced throughout the pandemic, often mentioning depression and anxiety in addition to their frustration with people who ignored COVID-19 restrictions. As one person we spoke with stated, when referring to those who did not follow guidelines, that these individuals thought only of themselves in making those choices. Many others said it was extremely stressful staying away from others for so long in addition to their constant attention to sanitizing. As this participant described it: "It's not even life anymore."

Participants said they felt isolated, and many avoided seeing family and friends. Some had very small social networks prior to the pandemic. The isolation during COVID-19 exacerbated their lack of connection and emotional support.

For those with preexisting mental health concerns, including anxiety and depression, isolation as well as fear about contracting COVID-19 exacerbated these conditions. We heard from people who experienced difficulties securing appointments with therapists or canceled psychiatric appointments given concerns about contracting the virus. Those who were able to access mental health therapy found it beneficial.

FEAR

In 2020, the research team conducted interviews for a related study of the general population regarding COVID-19 impacts and adaptations. That study focused on the broader population of Delawareans.[3] Preliminary findings from that study revealed many people were "worried" or "concerned" about the virus. What was different and quite striking about the conversations from this study with Delawareans living with HIV was how often participants used the words "fear" and "scared" - in addition to or instead of "concern" or "worry" – when describing their feelings about contracting COVID-19. They either directly revealed or implied that they saw the threat of COVID-19 as a life-or-death situation. One participant indicated, for example, that they did not care what was reopening – that they only cared about staying alive.

This sentiment was not limited to their own well-being. We spoke with people who cared for others – such as elderly parents – and expressed fear for them. Participants were also afraid for loved ones who did not follow public health guidelines, fearing they, too, may die. We spoke with one person who was in the hospital when the pandemic struck. Their concern initially was on their own health, but it quickly turned to their family members whom they could not visit with. As they recalled, "It was scary being in the hospital and looking out the window and seeing the world changing, and my family was out there."

COVID-19 and HIV

Important to highlight, the fear described did not tend to lead to inaction or helplessness. Rather, it typically precipitated strong adherence – to the extent constraints allowed – to public health recommendations and disciplined adoption of protective measures. In other words, fear led to action rather than inaction, and in a way that aligned with health guidance.

> *"I feel like I am a prisoner in my own house….The risk is too great. I'm [trying not] to die."*

COPING AND SUPPORT

Participants described some of the ways they were trying to cope with the stress of the pandemic. They mentioned such strategies as: watching television; drawing on addiction recovery strategies to cope with COVID-related stress; rearranging furniture, cleaning; talking to others on the telephone or through apps; listening to audiobooks; or reading. Other coping strategies included walking in parks, gardening, taking classes, and attending religious services either virtually or in a car outside.

To adhere to social distancing recommendations, participants found themselves cut-off from family members who might normally have provided in-person emotional support. One person who was hospitalized during the pandemic stated that the virus pushed doctors and nurses to step into that support role because families could not visit patients. Another lamented how the government should have prioritized opening social service and support agencies, instead of restaurants and bars, in the Spring and Summer of 2020.

Many participants noted a dire need for HIV/AIDS support groups in Delaware. They asserted this was a shortcoming even prior to the pandemic. The stay-at-home restrictions intensified the challenges associated with this lack of support. While some individuals benefited from support groups offered around other issues (e.g. addiction recovery groups), the lack of HIV support group options was repeatedly noted and left some clients without any options that met their needs. They emphasized how models exist in other U.S. cities and could prove beneficial for mutual aid support and socializing. During the pandemic, virtual support groups could have mitigated some of the isolation experienced by participants. Only 18% noted they had accessed online support groups of any kind during the pandemic.

Many participants in the study cited a very strong rapport with their case managers and pointed to how this support played a critical role for them. Some noted the need for event more routine personalized services and demonstrations of care to build trust. Eleven percent reported they had trouble communicating with their case managers or having their needs met during 2020. Stated another way, even with the challenges the pandemic introduced, 89% of those we spoke with did not report any communication challenges or unmet needs associated with their case managers.

COVID-19 and HIV

We did note that when rapport was not established prior to the pandemic or maintained during the surge in the early months, participants said they were less likely to reach out themselves with questions. Numerous people we spoke with were disappointed when they were unable to visit with case managers in person, highlighting how valuable they found in-person visits. Overall, participants hoped for guidance from case managers on how to best navigate the pandemic and the eventual vaccine roll-out plan. Some noted that a telephone phone call reaching out to them goes a long way. There seemed some level of inconsistency in how often, according to study participants, their case managers reached out to them. Some participants reported very frequent interactions, for which they expressed gratitude, while others indicated they only had monthly communications and were looking for more.

We note that, as researchers, we also had trouble reaching participants who signed up for interviews. We often encountered full voicemail boxes; no voicemail; no answering because (we later learned from them) they had not felt well at the time; delays because due to transportation challenges or sudden medical appointments, or sporadic work schedules. These same obstacles may have contributed to challenges participants had when trying to connect with potential support services, including with their case managers. Routine barriers to receiving care was likely exacerbated during the pandemic. Several study participants were very understanding of the challenges their case managers contended with, be it high caseloads or continuity of service during the COVID-19 crisis. Yet, it was because they found such support so valuable that they hoped the organizations providing case management would be able to secure the resources necessary to better accommodate their needs, including offering additional or augmented mental health support.

> *"These are decisions that could cost you your life, or someone else's life."*

GRATITUDE, UNCERTAINTY, AND RESILIENCE

We close by highlighting three different outlooks expressed by those we spoke with.

A few people we interviewed did not express concern about the pandemic, indicating that they were "not worried about anything [and would] just continue to do what [they are] doing." Some participants even described feeling "blessed" that they were not hungry, relatively well, and were able to pay their bills. Even as these participants expressed fear about some aspects, they conveyed either gratitude or chose to not focus too much on the pandemic.

COVID-19 and HIV

Other participants worried about the uncertainties surrounding the virus, its potential impacts on health, and the unknown side effects of the vaccine, given their other health conditions. They shared a sense of unease about when life would ever return to normal and when it might again be safe to see loved ones. As an example, one person we interviewed expressed concern that if they became sick, they might still avoid going to a hospital. The way they described it, their worry lay in how they might put their health at risk by putting too much focus on the risks associated with the COVID-19. Another client pondered how COVID-19 would never be gone and how it would always be in the air. The two cases illustrate an unease we heard from this group of participants, both about how COVID-19 might affect their lives and decision-making in the future.

A third and notable outlook was a resilient attitude. These participants described how they had experienced a great deal of hardship in their lives, including living with the challenges and stigma surrounding HIV. Thus, they felt they would be able to get through the challenges they confronted during the pandemic. It is important to note that even though some of these study participants pointed to fear and anxiety they had about the virus, they also identified with a sense of perseverance and strength.

> *"I learn to make do, that's just how I am. I've always been by myself….Parents threw me out of the house, I guess, for being gay and all that so I told them, you know what, I'm not going to cry about it. I'm going to show these people what I can do. I just don't deal with nobody. I'm great; that's why this little thing [the pandemic-related challenges] is a small thing to a giant—what I've been through."*

COVID-19 and HIV

SUMMARY OF FINDINGS

Our research team noted several key findings from this study of Delawareans living with HIV/AIDS.

1. Trust regarding information about the pandemic was greatest with local leaders and, in particular, with the doctors, nurses, and case managers they routinely relied upon for care. Protective action information dissemination (including information about testing and vaccination) should strongly utilize these sources.
2. Many participants experienced considerable economic hardship during the pandemic, often greater than they experienced leading up to the public health crisis.
3. These economic hardships would have been even greater if not for receiving assistance from case management and other support organizations; the ability to draw on savings; receiving extensive support from others in their network; or working multiple jobs, which sometimes increased their risk of COVID-19 exposure.
4. Those participants in smaller networks had fewer people on which to draw for support.
5. Many participants reported isolation, anxiety, stress, and depression, and indicated a need for greater mental health and emotional support.
6. Limited interaction with family or friends outside of the household may have intensified the need for emotional, mental health, and other assistance from social support organizations, even while the pandemic placed constraints on those entities.
7. Although some participants maintained or improved their health, many more suffered negative physical and mental health impacts during the pandemic or avoided/did not have access to some routine or emergent care.
8. Experiences with virtual medical appointments were mixed, with some participants finding them much easier than in-person appointments and with others finding them impersonal and inadequate in fully meeting their needs.
9. Many participants were anxious or worried about COVID-19. But they also described themselves as fearful of the virus and saw it as life-threatening for both them and those they care about.
10. By and large, participants tended to be very mindful of protective action recommendations, usually proactively following them and taking the virus seriously.
11. There were often circumstances out of their locus of control that put the people we spoke with at greater risk for contracting COVID-19 risk (e.g. employment, exposure to others in their household).
12. Given their exposure to others in their households and, sometimes, their employment, accesses to testing and vaccination is critical both for those living with HIV/AIDS as well as those they frequently interact with.
13. Findings revealed certain support strategies are needed to help Delawareans living with HIV cope with the pandemic.
14. Findings suggest that study participants' experience with HIV tended to generate fear of but also strong adherence to COVID-19 public health guidance. At times, it also led to an attitude of resilience in the face of another deadly virus.

Demographic Information

DELAWAREANS LIVING WITH HIV

According to the Delaware Division of Public Health (DDPH), at the time of this early 2021 study, 3597 Delawareans were living with HIV (all stages). 71.1% were male at birth and 28.9% female at birth. 57.9% were Black, 31.1% White, 8.3% Hispanic (all races), and 2.7% identified as other races.[4]

In 2020, the Ryan White Program served 1876 clients across seven program contractors (including the DHIVC). 66% of clients were male, 33% were female, and 1% were transgender. 25% were between 25-44 years old, 67% were between 45-67 years old, and 16% were 65 years or older. 71.4% resided in New Castle County.[5]

COVID-19 contributed to delays in compiling late-2020 statistical data for the 455 clients in the Delaware HIV Consortium's (DHIVC) database at the time of the study. In early 2020, however, when they served 375 clients, 57% of clients were male, 41% were female, and 2% were transgender. 72% of clients were African-American and 28% were White, of which 5.5% were Latinx (all races).[6]

A greater percentage of DHIVC clients are African American compared to Delawareans living with HIV overall. DHIVC also serves a greater percentage of women compared to the number of Delawareans living with HIV and those served by the Ryan White Program, although the wording of this information differs between DDPH and DHIVC reports in important ways (gender versus sex assigned at birth).

PARTICIPANT DATA

In our study, participants were asked an open-ended question to self-identify their gender and their race/ethnicity. 48% identified as male, 50% as female, and 2% as transgender (one person chose not to self-identify). 53% self-identified as Black or African American, 25.5% as White or Caucasian, 5.5% as mixed or more than one race (which, in one case, was Caucasian/African American), 5.5% as Hispanic/Hispanic, Puerto Rican/Latino, 3.5% as either American Indian or both White and Native American. 7% listed American, None or Not Sure. Although our sample includes slightly more females than males, when compared with 2019 data from the DHIVC, it is relatively close in racial/ethnicity to the clients served by the DHIVC, with slightly fewer identifying as White or Caucasian, although the wording of our question did allow participants to self-identify as Latino/a/x or Hispanic without choosing a race.

Our respondents ranged from 32-71 years old, with an average age of 55. 15% were between 25-44 years old, 76% were between 45-67 years old, and 9% were 65 years or older. In other words, slightly more study participants were in the 45-67 age range compared to Ryan White Program clients. In our study, 69% lived in New Castle County, 20% in Kent County, and 11% in Sussex County. This is a similar distribution of those who live in the more populous New Castle County as clients served by the Ryan White program.

When study participants were asked about annual household income for 2019, the year prior to the pandemic, 21.5% earned under $9999; 35% earned between $10,000-$19,999; 8% earned between $20,000-$29,999; 21.5% earned between $30,000-$39,999; and 14% earned between $40,000 and $69,999. Four participants chose not to respond. Although were do not have the household composition information to calculate the number who live below the federal poverty rate and directly compare with Ryan White Program clients, with over 55% with annual households under $20,000, our study does include participants who experience similar levels of economic hardship.

Methods

This study - COVID-19: Community Impacts and Adaptations to Crisis: Delawareans Living with HIV/AIDS - was supported, in part, by a contract from the Delaware HIV Consortium (DHIVC) and with funds from the University of Delaware's Disaster Research Center (DRC). The study design drew from an ongoing, independent study COVID-19: Community Impacts and Adaptations to Crisis,[3] where over 300 Delawareans were interviewed in the Spring and Summer of 2020 about their pandemic experiences. Although we hope to eventually directly compare results, this report focuses strictly on findings from our study of Delawareans living with HIV/AIDS.

DHIVC distributed a recruitment letter by mail to 455 individuals in December 2020 (16 letters were returned unopened). This constituted the total number of clients in their database at the time. The letter included information about the study, a statement of informed consent, and the University of Delaware telephone phone number of the lead DRC investigator for potential participants to contact if they wished to sign up for the study. Participants were told that clients of the DHIVC who completed the interviews would receive a $100 gift card for their participation. Some participants who left messages did not answer return calls or did not leave clear call-back information. Others were unable to participate due to limited availability during the study period.

Seventy-five interviews were scheduled for January and Februar 2021; however, 20 people needed to cancel given other commitments or difficulties connecting, or they did not show up for their scheduled virtual/telephone interviews and were unavailable when we again reached out by telephone. In total, 55 telephone or Zoom virtual interviews were completed by DRC researchers, which constitute approximately 12% of DHIVC clients at that time. Interviews lasted approximately 30-150 minutes. All were audio recorded. Cameras were not activated during Zoom calls to maintain confidentiality and privacy. Data was retained by DRC and is only reported in aggregate or by using pseudonyms.

Participants were informed prior to the interviews that those wanting to receive the gift cards from DHIVC would have only their names and telephone numbers provided back to the organization and that DHIVC would distribute the gift cards directly. Participants had the option at the beginning and the end of the interview to decline the gift card, and not have their name shared with DHIVC. All study participants who completed interviews chose to receive the gift cards. Funds for the gift cards were provided by DHIVC. The study had human subjects research approval through the University of Delaware Institutional Review Board.

Nine health-related questions were asked of all participants, in addition to demographic questions. Frequencies for these answers are shared as percentages in this report. Most of the interviews, however, utilized a semi-structured open-ended format. Questions were consistent across interviews, focusing primarily on their experiences, the challenges they confronted, adaptation and coping strategies, modes of communication, and sources of trusted information and guidance. That said, the qualitative approach resembled a guided conversation where the interviewer probed for additional information based on participant responses. Over the lengthy conversations, the goal of the research was to focus on depth of understanding over breadth, on the how and why their experiences, and to focus on discovery, rather than verification.[7]

Analysis for this report was conducted independently by the authors and does not necessarily reflect the views of DHIVC.

> *"We had to change because the world changed…it was a big change in my life."*

Footnotes

Cover Photo: Drive-through testing event, Seaford, Delaware, May 2020. U.S. Army National Guard photo by Capt. Brendan Mackie.

[1] The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was enacted in 1990 to improve care for low-income, uninsured, and underinsured individuals and families affected by HIV. The state of Delaware is a recipient of Ryan White Program Part B funds, which is disbursed to all states and eligible U.S. territories to help improve the quality, availability, and organization of HIV/AIDS health care and supportive services, and also to provide access to high-cost pharmaceuticals through the AIDS Drug Assistance Program (ADAP). The Ryan White Program (RWP) allocates funds to states for direct health care and the provision of support services for people living with HIV. This assistance serves people with no regular source of health care and people with Medicaid or private insurance whose HIV-related care needs are not being met by other providers. In Delaware, grants from the Ryan White CARE Act and the U. S. Department of Housing and Urban Development's Housing Opportunities for Persons with AIDS (HOPWA) program also support the Delaware HIV Consortium's Housing Assistance Program, a statewide rental assistance program that provides help for low-income persons living with HIV and their families in Delaware. Accessed on March 1, 2020 at: https://dhss.delaware.gov/dph/dpc/hivtreatment.html *and* https://www.delawarehiv.org/housing-programs/ *and* https://targethiv.org/sites/default/files/supporting-files/PlanningCHATT-Module1-QRH1.pdf

[2] The population of Delaware in 2019 was estimated at 973,764. As of February 11, 2021 (with interviews were completed), a total of 82,263 positive cases of COVID-19 in Delaware had been reported to DPH since March 11, 2020. Accessed on March 1, 2021 at https://www.census.gov/quickfacts/DE *and* https://news.delaware.gov/2021/02/13/weekly-covid-19-update-feb-12-2021-new-positive-cases-flatten-as-hospitalizations-trend-downward/

[3] Bryant, Tracey, 2020. How is COVID-19 Impacting Delawareans? UDaily. University of Delaware. Accessed on March 1, 2021 at https://www.udel.edu/udaily/2020/may/disaster-research-center-covid-19-study-delaware/

[4] Delaware Division of Public Health. Monthly Surveillance Report through Jan 2021. Accessed on March 1, 2021 at https://www.delawarehiv.org/wp-content/uploads/2021/02/monthly-surveillance-report-through-Jan-2021-1.pdf

[5] Delaware Health and Human Services, Division of Public Health, Health Promotion and Disease Prevention. (2021) Ryan White Public Hearing PowerPoint Presentation. Ryan White HIV Care Grant Program: Part B: Health Resources and Services Administration. (March 17).

[6] Delaware HIV Consortium 2020 Annual Report. Accessed on March 1, 2021 at https://www.delawarehiv.org/wp-content/uploads/2020/08/2020-Annual-Report.pdf

[7] Ambert, Anne-Marie, Patricia A. Adler, Peter Adler, and Daniel F. Detzner. "Understanding and Evaluating Qualitative Research." Journal of Marriage and Family, 57, no. 4 (1995): 879-93. Accessed March 1, 2021. doi:10.2307/353409.

Additional Information

THE DELAWARE HIV CONSORTIUM

The Delaware HIV Consortium was founded in 1991 as a non-profit corporation in the state of Delaware. The agency is an HIV service provider offering support services for Delawareans living with HIV, and a range of education and prevention services to help Delawareans avoid HIV infection. The Consortium provides these services as a result of contracts with the Delaware Division of Public Health, the City of Wilmington, the Delaware State Housing Authority, and because of community giving. Its case managers provide services from their Wilmington and Milford offices. The HIV Case Management program, funded by the Ryan White HIV/AIDS Program through the Delaware Division of Public Health, provides case management services to help clients live more productive lives through medication management, adherence to medical treatment, and connecting them to supportive services like housing assistance, health insurance assistance, mental health services, transportation, emergency financial assistance, and referrals to social and supportive services.

THE DISASTER RESEARCH CENTER

The Disaster Research Center (DRC) at the University of Delaware is the oldest center in the world focused on the social science and management aspects of disaster. For nearly sixty years, the Center has examined a broad range of issues related to the social, behavioral, community, and organizational aspects of disasters. DRC is committed to advancing the state of the art in disaster research and its scientifically guided practice; educating the next generation of disaster science scholars and informed practitioners; and creating, gathering, and disseminating disaster knowledge in a dynamic and responsive way.

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