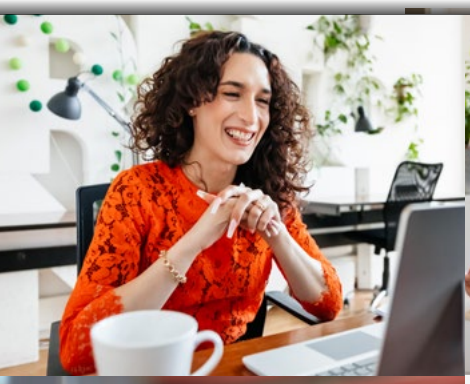
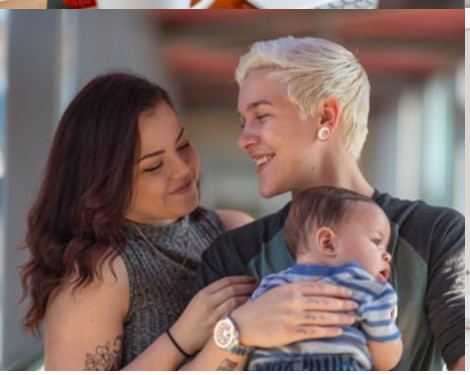





MID-ATLANTIC TELEHEALTH RESOURCE CENTER
COMMUNITY RESPONSE TOOLKIT

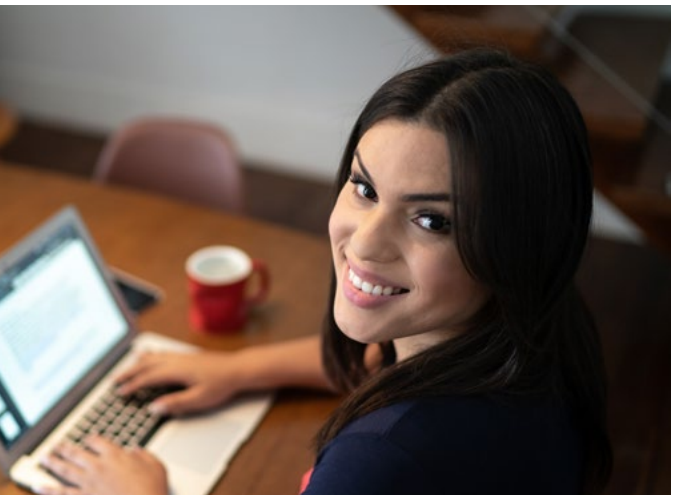
Trans-Mission: Leveraging Telehealth for Care, Support, Advocacy and Education in Central Virginia for Trans and Non-Binary Individuals, Their Support System, Families and the Community During the COVID-19 Pandemic

Transgender Telehealth Services

Created in partnership with:

Georgetown University School of Nursing (GU), Mid-Atlantic Telehealth Resource Center (MATRC), BlackTransmenInc (BTMI),, Totier Telehealth Partnership (TTP), Transgender Health Alliance of Central Virginia (THACVA), Virginia League for Planned Parenthood (VLPP)

Statement of Problem



Gender-diverse patients have a long history of limited resources, social isolation, few supports, and often an aversion to healthcare due to fear of discrimination by medical professionals and healthcare systems[1]. This reality was exacerbated during the COVID-19 pandemic as individuals found themselves further isolated and struggling to access vital but limited healthcare services[2, 3].

Multiple service providers and organizations serving transgender patients in Central Virginia rallied, beginning in March 2020, to better coordinate services due to

Overall Background

conditions of isolation and restriction of access caused by the pandemic.

These efforts included: vigorous planning using video-conferencing tools, greater deployment of telehealth for clinical services including hormone replacement therapy, and increased coordination between service organizations for support.

Multiple studies indicate transgender patients, compared to cisgender individuals, reported significantly higher family rejection (and loss of housing/food insecurity), lower social support, higher loneliness, higher depression, lower protective factors, and were less certain in avoiding sexual risk behaviors[4,5].

The pandemic quickly revealed that isolated and vulnerable patients such as inmates, the elderly, individuals in congregate living, the developmentally disabled, and isolated members of the LGBTQ+ community were at significant risk from COVID-19. The deep inequities in obtaining access to healthcare were especially true for transgender and non-binary (TGNB) patients[2, 6].

TGNB patients have been uniquely affected by the pandemic in several ways, including:

- Risk of exposure to the virus and its adverse outcomes
- Delays in access to testing, vaccinations, gender-affirming care, including cancellations of medically necessary transition-related surgeries (surgeries, for example, were canceled March-June 2020 due to PPE/bed shortages)
- Diminished access to social support, which is crucial to protecting against the effects of stigma, discrimination, mental illness
- Numerous legal and interpersonal challenges and limits on transgender rights
- Economic hardship with a high loss of work in many job sectors (public-facing jobs deemed essential faced a higher rate of COVID exposure)

In this context of isolation and attendant mental health issues, TGNB people have the need to comprehensively plan in advance to ensure access to complex, medically necessary gender-affirming interventions, such as top surgery from supportive, well-trained providers.

Overall Background

Mid-Atlantic Telehealth Resource Center

Cancellations or postponement of medically necessary procedures by hospital systems can prolong suffering and hardship in what can be an already challenging and circuitous process. The complications of travel during COVID-19, such as travel restrictions, quarantines across states, and risk of infection, also limited people's options to obtain gender-affirming care in other states or countries.

Social Factors

TGNB individuals, particularly those patients of color, often have higher rates of complex social issues including housing, access to technology and the lack of a safe space to acquire care. Even homeless shelters, for instance, can be gendered, and block people who are trans and/or non-binary from entering a shelter.

In addition, during the early days of the pandemic, unstable housing situations, employment, and support resources became so exacerbated that many of these individuals who needed access to programs simply "fell off of the cliff." These patients also can have significant mental health issues and substance abuse problems along with negative coping skills. The pandemic unfortunately was a perfect storm to further isolate a very vulnerable population[7, 8].

Although the COVID-19 pandemic compounded many existing disparities, the most notable was ***markedly reduced access to expert clinical care***. As authorities called for measures to mitigate the spread of COVID-19, delays occurred in accessing gender-affirming health services. For example, the cessation of non-emergent but necessary surgeries effectively shut down gender-affirming procedures and further delayed access to medically necessary procedures for transgender and gender diverse people[3].

Finding new trans-competent sources for evaluations for gender-affirming hormone therapy was difficult as healthcare systems had limited enrollment and prioritized patients already established in their system, particularly for rural patients. While the pandemic severely curtailed access for existing patients within health systems, it left many new patients without options except for telehealth.

Telehealth Issues

Mid-Atlantic Telehealth Resource Center

Unfortunately, many of the isolated, trans-population members are not skilled with video-technology services. Some patients drive for hours for their care in this case. Other patients, often older adults in rural areas who lacked proper technology and broadband, initiate telehealth by phone only until they are able to be seen in person through video during the pandemic[9].

Patients contend with limited broadband, older devices, service disruptions and lengthier wait times to reach a healthcare provider for gender-affirming hormone care, and many planned surgeries were canceled due to COVID-19 and the attendant PPE shortages in early 2020. In addition, acquisition of gender-affirming hormones including syringes and needle supplies was challenging.

Other challenges included coordination of care with laboratory results and vital, frequent refills of needed medication for gender-affirming hormone therapy (GAHT). Additionally, patients who needed to find housing were forced to move out of state to friends or family members. A prescription valid in one state, for example testosterone, could not be transferred. Many patients also had to scramble to find gender-affirming providers in their new home able to continue with their hormones.

In particular in Central Virginia, patients who live in rural areas experienced continuing inequities with isolation and broadband access. Healthcare clinics not using telehealth pivoted throughout the spring of 2020 to providing services via telehealth in order to meet patient demand, continue health services and fulfill their mission. Transgender patients, however, were often the last to receive education, information and support. Most often they traveled long distance to tertiary care centers to seek care.

Assad and colleagues (2020) note the further challenges for patients seeking trans-affirming care via telehealth during the pandemic[10]:

- Legal implications of providing care if the patient is in a state where the clinician is not licensed
- Inadequate reimbursement for telemedicine services
- Difficulty with establishing trust and rapport remotely
- Inability to perform a physical examination or acquire direct laboratory specimens
- Lack of clinician experience with telemedicine (including practical concerns, documentation requirements, etc.)
- Lack of high-speed internet connection
- Technology limitations as patients often relied on older cell phones as their primary source for connection
- Lack of private space for the patient to attend telemedicine visit

Overall Background

Mid-Atlantic Telehealth Resource Center

Thanks to the temporarily revised telehealth policies that were quickly put in place during the national and state pandemic emergency declarations, both patients and healthcare providers adjusted to a new normal. As a result, alliance groups and providers in Central Virginia had numerous meetings beginning in April 2020 to coordinate efforts.

As an example, Virginia League for Planned Parenthood (VLPP), a large provider of TGNB services, quickly implemented processes to schedule patients for telehealth visits. This included using HIPAA-compliant videoconferencing for healthcare provider collaborative meetings. Asynchronous technology also provided access for patients to obtain needed birth control, assessments for urinary tract infections, or emergency contraception.

Additionally, a number of agencies and healthcare professionals were able to provide telehealth as a lifeline to patients to continue gender-affirming services that they had been receiving. Organizations such as UVA Health Gender Affirming Services, VLPP and the Complex Care Clinic at VCU were able to conduct intakes for new patients. These intake visits were performed using informed-consent via telehealth on a HIPAA-compliant platform. The ability to drive to a clinic or laboratory for needed labs (generally every three months during year one) remains challenging for many patients.

Anecdotally, those who began GAHT during this time were able to sometimes transition slowly at home, and enjoyed the privacy during this time. These patients expressed that the ability to transition medically without the stress of being negatively observed by outsiders in a public clinic environment was a relief. Other patients noted being able to access care at work on their smartphone or mobile device, and find a quiet space to talk to a clinician about their health and needs. Teens under the age of 18 need parental permission to obtain GAHT including through telehealth.

Intakes and continuance of care for mental health services were crucial during COVID. Some communities such as the Transgender Healthcare Alliance of Central Virginia were able to use a group email setting to share services that offered

Overall Background

mental health services for trans and non-binary patients. Some online web-based support services for group therapy, mentorship, voice training or information sharing (such as injection trainings) were also provided.

As health care organizations rapidly created online access, patients especially began to use their limited resources to pursue care. Some of the most important steps for self-care and advocacy shared through support organizations included patient efforts to:

- Be proactive about their health needs
- Anticipate shortages for medications or supplies
- Make their healthcare appointments long in advance
- Know who to talk to if they needed more emergent help
- Recognize key allied healthcare support such as social workers, case managers and referral coordinators. Call centers for clinics in this case were the key to success in management for the nuances of care
- Increase the use of web-based education and support resources (examples include TransBlackMenInc or THACVA)
- Aggressively seek provider letters of support for surgeries or other referrals

Approach & Infrastructure

Self-identifying trans-health and gender-affirming clinics along with TGBN support resources and community organizations with telehealth platforms are an important way for patients to access gender-affirming care and was the guiding objective of providers in Central Virginia.

With coordinated outreach between groups, TGBN individuals were encouraged to use web-based searches including the resources of the academic centers (UVA, VCU) to discover online support resources (THACVA), providers who are gender-affirming, and alliance groups TransBlackMen). Once a patient is established and has sought care in a clinic through an appointment, the use of telehealth is being used as a strong platform from community settings and home to educate, obtain initial intakes about health status, and to have meaningful conversations about health and well-being goals. It also continues to be used to educate about safety, testing and vaccinations during COVID.

Approach & Infrastructure

Mid-Atlantic Telehealth Resource Center

Key Considerations Learned for Workflow and Clinical Processes:

- Ensure distribution of key support sites on well-established web sites
- Provide local patients, contacts, and resources within the region
- Connect with transgender alliance groups to promote use of telehealth
- Promote telehealth training sites for providers
- Provide organizations with access to their regional telehealth resource centers
- Identify and promote those providers who offer gender-affirming services
- Establish use of HIPAA-compliant telehealth platforms
- Offer brief and simple use instructions with links to download on computer or phone
- Ensure communications should be gender affirming
- Training is necessary to learn specific terms and become literate with gender-affirming statements and approaches such as the use of names, pronouns and an expansive view of gender and treatment protocols
- Recommendations to providers on WPATH standards
- Review processes with alliance groups and TGNB individuals
- Enable tele-mental health services to be readily available, including suicide prevention and crises hotlines
- Ensure access to a private room or space to talk freely without intrusion or coercion
- Follow all guidance on telehealth etiquette
- Test to ensure access to Wi-Fi or adequate cell connections
- Referrals to alliance groups should be a standard action
- Consider all state regulations regarding minors (under age of 18) and patient's capacity for consent

For telehealth providers, recommendations and standards for initial telehealth patient intakes and healthcare have been updated per the World Professional Association for Transgender Health called the Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People (see website links in Appendix). Clinics have been historically using an informed-consent model with licensed and non-licensed mental health providers (social worker, psychologist, nurse practitioners) who can initially assess the patient's gender dysphoria and document the needs for gender-affirming healthcare to include hormone therapy.

Gender Affirming Hormone Therapy (GAHT) services should not be seen as "approving" services for hormones or confirming their dysphoria, but that these notes are helpful for insurance and for identifying potential needs for patients.

Approach & Infrastructure

Mid-Atlantic Telehealth Resource Center

Safe, face-to-face, in-person encounters are going to be required at key moments in the process.

A roadmap for gender-affirming care through telehealth should include:

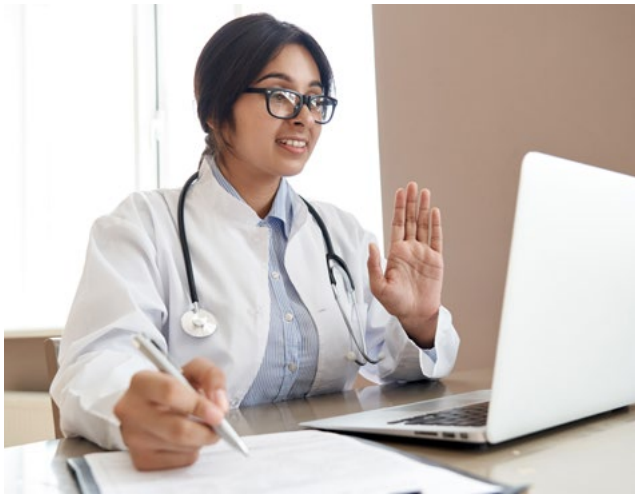
- Processes for ongoing lab work
- Self-injection trainings
- Prescription process for supplies such as needles and syringes
- Detailed follow-up care
- Expectations regarding hormone therapy and information for patients regarding their care
- Reproductive health or fertility referrals prior to initiation of hormone therapy

Active provision of community links to support group and adjunct therapies must include resources on:

- Mental health
- Mentorship
- Support groups
- Voice therapy
- Hair removal
- HIV services
- Housing
- Individual/family/partner therapy
- Resource workbooks on above and other key topics

Mentorship and training for healthcare providers needing guidance for mental health and medical care are also part of this community process during COVID-19 and include:

- COVID-19 education including promotion of vaccines and screening for illness
- Education of medical, nursing, and allied healthcare studies about gender affirming work, including processes using telehealth, language, communication, funding and payment resources



Key Stakeholders

Collaborations between inter-agency, inter-professional, community-based alliances are critical to expanding telehealth resources to isolated groups during a pandemic. Highlighted by the pandemic, partnerships between academic healthcare, health systems, providers and advocacy groups became critical. See list of partnerships in Central Virginia in Appendix.

Critical Success Factors and Best Practices

Given the myriad of social and medical issues surrounding quality care and the use of telehealth in the TGBN community, it is critical to ensure that robust communications between providers, community groups, medical systems and advocacy organizations are enabled. The region still has a significant distance to travel to achieve this but the work has begun. This also fundamentally requires the engagement of TGBN individuals, friends, families and allies.

Much work is still necessary to design a reasonably seamless telehealth network following acceptable standards and means for connection, education, and broadband expansion. Unique populations like TGBN individuals in prisons and congregate settings needs to be advanced, especially to include improved telehealth services within Department of Corrections facilities and nursing homes.

Specific recommendations for healthcare personnel include attendance at evidence-based conferences and trainings on transgender health (WPATH SOC, Philadelphia Trans Wellness Conference, UCSF Guidelines of Excellence) and seeking gender-affirming educational training about care to include:

- Overview of intake
- Review use of pronoun in gender-affirming telehealth care
- Communication techniques
- Understanding approaches to the physical exam using a trauma-informed care model

Critical Success Factors and Best Practices

Mid-Atlantic Telehealth Resource Center

Providers should be engaging and comfortable with emerging evidence-based science research regarding best practices for gender-diverse patients with an awareness that this is not a pathological condition. Barriers to health care and other concurrent difficulties should be seen through a minority stress model.

Information regarding legal facets of care need to be more broadly understood to include:

- Gender marker changes
- Social security name and gender changes
- Immigration, passport and driver's licenses or other IDs
- Insurance coverage during this time

Knowledge of local/state reputable trans-friendly surgical resources and mental health trans-friendly resources is paramount.

Lessons Learned

There continue to be significant lessons learned in integrating telehealth into the complexities of interprofessional transgender care. Some of our region's most critical lessons are:

- Organizations that offer gender affirming care with or without telehealth must work within the broad context of community organizations and advocacy groups.
- TGNB individuals have complex healthcare and social needs. It is not suitable to use telehealth to simply connect for transgender patients without understanding the resources that are needed.
- Because of isolation and many patients living in rural settings with limited broadband, TGNB individuals have a difficult time finding access to broadband capability; they often have older phones and limited technology.
- While connectivity is difficult, telehealth does work for TGNB and should allow for a safe atmosphere for both mental health and physical health encounters without losing communication subtleties. It must continue beyond the pandemic.
- Telehealth has proven to be a helpful clinical resource to secure hormone therapy, follow-up visit for refills and for appropriate health services,

Lessons Learned

education and group therapy.

- The tools used in telehealth can be effective in linking TGNB patients to one another in supportive environments as well as for connections within regional alliances.
- Web-based tools and HIPAA-compliant telehealth platforms can help facilitate providers to provide mutual support, training, quality improvement for best practices.
- Training is essential for novice providers to help create a safe environment
- Training in communication, appropriate clinical questions, language, names, confidentiality and pronouns is essential in creating a respectful environment.
- Much more research is needed to determine the impact and effectiveness of telehealth for TGNB care.
- Barriers to care for transient TGNB patients is constant and so warm handoffs or knowledge of resources is helpful.
- The intersectionality of TGNB and healthcare culture should always be considered when noting the social determinants of care and the individual needs
- TGNB patients will rely on GAHT for their life—these patients are resilient despite their vulnerabilities.
- TGNB patients are at a safety risk and are targets of violence from hate groups or individuals - telehealth can help enhance safety.
- TGNB patients often have trauma histories associated with their mental health and need access to mental health provider networks to support them; tele-mental health resources are essential.
- The role of the patient in designing care through in person clinics or face to face virtual care is critical.

For TGBN patients, the primary lessons were and continue to be:

- Patients are able to initiate or continue their transition at home in isolation through the use of telehealth technology.
- Access to support groups and advocacy decreased and people find themselves even more isolated.
- Patients who take ownership of their health and followed through with their care to include necessary labs experience better outcomes
- Patients who are motivated to improve their healthcare status—and self-reporting behaviors of quitting nicotine, changing harmful habits of coping through substance abuse and engaging in their health are most successful.

The individual data of outcomes in patient care is not available to this collaboration at this time. As the major academic centers move to improve access and awareness of the issues of trans and non-binary patients, increased use of telehealth can help overcome the barriers of time, distance and isolation.

Although not measured during the pandemic, if resources and support are provided to TGNB patients, they begin to thrive and live more fully authentic lives, often times finding a network of friends and community that celebrate them and support them. Filling in the needed education about gender-diverse patients helps individuals, families, providers and communities understand the lives and needs of these people. Although the changes in language and use of pronouns might feel unfamiliar, these affirming gestures are critical for patients to feel recognized, accepted and respected on a micro and macro level.

Appendix

Support Sites and Resources

- UCSF Center of Excellence for Transgender Health:
  https://prevention.ucsf.edu/transhealth
- The UVA Health System Gender Health and Transgender Health Services who provide comprehensive, inter-professional gender affirming clinical care including Teen Health's Transgender and Youth Health Services as well as Student Health:
  https://uvahealth.com/services/transgender
- Virginia Commonwealth Health System which provides complete, interdisciplinary transgender care within adult care and the Children's Hospital:
  www.chrichmond.org/services/transgender/transgender
- Virginia League of Planned Parenthood who is a primary care resource for a number of TGNB individuals:
  www.plannedparenthood.org/planned-parenthood-virginia-league/for-patients/transgender-services
- BlackTransMen,Inc who serve as both an educational and advocacy resource along with community organizing and mentorship:
  www.blacktransmen.org
- World Professional Association for Transgender Health (to include USPATH) serves as a guide for clinical standards of care (SOC), communication, practice issues and certification:
  www.wpath.org
- The Transgender Health Alliance of Central Virginia (THACVA) serves as a local education and advocacy group for peer mentoring and education:
  www.thacva.org

- The Women's Initiative, counseling resources:
  https://thewomensinitiative.org
- ReadyKids counseling for teems with gender dysphoria:
  https://readykidscville.org
- Maynard's W.I.S.D.O.M., Inc for workshops/training and workbooks (a series) for Teachers/Educators, Parents/Families, and Partners/Loved Ones of those who are gender-diverse. Classes were provided during the pandemic to regional teachers:
  https://maynardswisdom.com
- Virginia Department of Health - Statewide transgender resources through the Virginia Transgender Resource and Referral List:
  www.vdh.virginia.gov/content/uploads/sites/10/2019/04/TransRRList.pdf
- PFLAG for parent support when their children transition:
  https://pflag.org
- Lambda Legal for guidance on legal issues/human right's issues for TGNB patients:
  https://www.lambdalegal.org
- Charlottesville Pride Community Network, a broad venue for local resources:
  http://cvillepride.org/local-lgbtq-friendly-business-service/transgender-resources/

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