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Improving Equitable Transition to Adult Care for Transgender and Gender Expansive Adolescents and Young Adults

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Abstract: Transgender and gender expansive (TGE) adolescents and young adults are a marginalized group who have many health disparities in relation to their cisgender peers secondary to transphobia and cis-normativity, with TGE people of racially minoritized identities also having to navigate the intersection of racism. One area of TGE care with little to no research, yet that has the potential to help improve overall wellbeing of TGE individuals, is transitioning care from pediatric to adult care. In other medical specialties, such as diabetes management and mental health, transition of care (ToC) interventions have been correlated with positive health outcomes. In this paper, we explore how ToC may be tailored for TGE adolescents and young adults through an anti-racist and health equity lens using a current review of ToC interventions in other realms of care. Four domains of ToC were identified in the review: planning for transition, transfer assistance, integration into adult care, and care coordination. We explore TGE specific intervention recommendations for each domain, with additional recommendations for how to approach research in this area. ToC from pediatrics to adult care is a vital time for all patients, and improved ToC has been correlated with better health outcomes. Tailoring ToC interventions to TGE adolescents and young adults may help to address health disparities in this group.

Keywords: Transition of Care, Transgender, Gender Expansive, Health Equity, Adolescent

1. Background

The transition of pediatric to adult medical care is fraught with obstacles, including loss of caregiver guidance and developmental perceptions of health and risk behavior [1]. Furthermore, the majority of youth do not receive any transition of care (ToC) planning [1], despite current research that shows successful ToC is associated with improved morbidity and increased self-satisfaction and self-care independence [2]. Youth with marginalized identities must additionally navigate structural and ideologic barriers as they transition care, which can contribute to health disparities [1, 3]. For transgender and gender expansive (TGE) adolescents and young adults, there is little to no research on how best to address ToC [4].

The terms *transgender* and *gender expansive* are used to describe those whose gender identity does not align with the sex presumed at birth and/or those who identify outside of the constructed gender binary altogether [5]. TGE adolescents and young adults may seek medical interventions, known as gender affirming medical care, for their transition, the journey that these individuals experience as they explore the vast facets to their identity [5]. Importantly, gender transitions do not have a standardized endpoint, and may change and evolve over time [6]. This makes the continuous care of TGE people important to ensure that TGE patients are consistently supported, and that there are no periods without care which can lead to seeking medical treatments, such as hormones or silicone injections, from unlicensed sources [5]. Even for TGE adolescents and young adults who do not seek

gender affirming medical care, there is still a need to ensure safe ToC, as up to 25% of surveyed TGE adults have refused to seek urgent medical care due to previous negative experiences with unknowledgeable and at times abusive providers [5]. TGE adolescents and young adults already experience a high burden of health disparities, including decreased use of primary care services and increased rates of HIV and suicidal ideation/attempts compared to cisgender adolescents and young adults [7], due to transphobia and cis-normativity that TGE people experience every day [8]. Improving ToC, with an emphasis on respectful and inclusive care of TGE people, may mitigate the burden of health disparities, decrease the utilization of the emergency department as a source of primary care [9], and help prevent lapses of preventative care [10].

2. Crafting Specific Transition of Care Recommendations

When talking about any medical care for TGE people, we must acknowledge the long history of racism and transphobia in medicine that has hurt the TGE community, especially TGE people of color [11]. TGE people of color have been more likely to be disbelieved by providers than White TGE people and therefore have been disproportionally forced to seek care outside of medical systems [5, 11, 12]. Furthermore, medicine had a history of using the bodies of racially minoritized people for experimentation, and much of what we know about reproductive medicine and gender affirming procedures comes from non-consensual and forced experimentation done on Black bodies [11]. Specifically for ToC, acknowledging this history is important as this history creates additional barriers for TGE people from racially minoritized communities that White TGE people do not face. This becomes apparent when looking at the existing TGE research, which features predominantly White representation [13, 14]. Therefore, all interventions aimed at improving ToC care should be carefully evaluated for how they might affect racially minoritized groups (including hearing the perspectives of these groups), and should be catered to the different social barriers that TGE adolescents and young adults face based on racial/ethnic oppression.

We can further ground suggestions for TGE specific ToC within a recent systematic review on ToC by Schmidt et al (2020) [2]. Schmidt et al's review found that ToC interventions could be grouped into four overarching categories: planning for transition, transfer assistance, integration into adult care, and care coordination. Outcomes were also grouped into four categories: adherence to care monitoring, disease specific measures, patient-reported health and quality of life, and self-care. Importantly, only two of the 19 included studies were ranked as strong quality, and specific demographics were not included. This is important to clearly identify as ToC interventions that have worked for certain groups may not work for others [15, 16]. We can still use this framework as a scaffold to suggest the following ideas for approaching ToC interventions for TGE adolescents and young adults. While these suggestions are listed separately, they are best used all together, as all studies in the review with positive outcomes used a combination of interventions [2].

3. Planning for Transition

When considering planning for transition, interventions should focus on the importance of trust in TGE continuous care [17], given the medical community's treatment of TGE people. We would suggest that conversations around ToC begin at as early as possible, to give adolescents and young adults time to start internalizing this change. The Got Transition ® program recommends starting these conversations as early as 12-14 years old [1]. While this may seem premature, addressing ToC early may help calm any fears of abandonment in a trauma informed framing [18]. These conversations around ToC can be broached as empowering TGE adolescents and young adults to continue exploring their identities and stressing the importance of having a trusted medical provider as a resource throughout their life. Framing the transition this way places the power in the hands of TGE adolescents and young adults rather than the provider, which can mitigate the historical power dynamics between medicine and the TGE community [7, 11, 12]. Providers should thus spend time talking with TGE adolescents and young adults about their goals both in their gender journeys and in life, to best identify how healthcare providers can support them on these journeys.

4. Transfer Assistance

To improve transfer assistance, ToC interventions for TGE adolescents and young adults can focus on identifying multiple (if possible) vetted adult providers in the community. Providers who are TGE friendly can be identified through TGE community approval. While this can be fraught with bias, there are very few ways to accurately determine an individual's cultural humility around TGE topics [19]. Additionally, word of mouth is currently the way in which many TGE people know which providers are safe [20], so this method is already well established in the community. If no TGE friendly providers have been identified by the pediatric clinic, the practice can ask their former TGE patients who have graduated to adult care which providers have been TGE friendly. There are also efforts in place to create list serves of TGE friendly providers across the nation [20], which may be especially useful if the patient is moving. Having multiple providers helps to ensure that there are openings for new patients, and that each patient can find a provider that they feel comfortable with. The ability to identify multiple providers who can provide TGE care is not possible for many communities, due to the allocation of TGE care to specialists [5]. Therefore, ToC interventions can also work to move TGE care from specialized clinics (adolescent clinics, tertiary gender clinics) to primary care clinics. This

will improve ToC in many ways, such as avoiding the long waiting lists that specialty clinics have, and by consolidating care, as primary care providers are able to give desperately needed preventative and whole-body oriented care in addition to providing gender affirming care [21].

5. Integration into Adult Care

As part of integration into adult care, providers of TGE adolescents and young adults should consider being available to their patients until they have articulated that they feel safe and comfortable with their new provider. This overlap will provide a trusted source of care during the transition. Introductions can be made well ahead of when ToC will occur, to ensure that providers and TGE adolescents and young adults connect well. Furthermore, pediatric offices can work with adult providers on anticipated self-care skills. In a TGE context, this may involve taking gender affirming medications and navigating medication refills on one's own. A non-medical provider member of the pediatric or adult team can provide close assistance in these early months of independence by calling with reminders and helping schedule appointments. Finally, we recommend that adult providers ensure that their offices are safe places for TGE people. This falls within standard recommendations for caring for TGE people and is not specific to ToC [22]. However, a negative experience, whether it be with the front desk or even signage within the building, can deter someone from seeking care [5]. For newly independent TGE people, who are already needing to navigate so much, these experiences can contribute to loss of follow up [5], especially when they are a new patient and have not yet established a trusting relationship.

6. Care Coordination

Incorporating community members as peer navigators could help improve ToC by having people with similar experiences guide TGE adolescents and young adults. This model has been successfully used with the TGE community in HIV work to increase service utilization and reduce transmission rates [23, 24]. Peer navigators could help introduce TGE adolescents and young adults with different adult providers and elucidate if the meeting went well or poorly, thereby keeping track of which adult providers a patient is most likely to have a good healthcare relationship with. Another possible way to incorporate peer educators would be to have them spend time with the TGE adolescents and young adults exploring healthcare goals and discussing why follow up with a primary care doctor can be beneficial. This can help with the time restrictions many providers face with patients. We acknowledge that many offices do not have the resources to hire an additional staff member; however, we suggest that pediatric clinics discuss jointly hiring someone with an adult clinic to help reduce each clinic's respective monetary burden. Joint hiring practices would also help with integrating ToC into not only the pediatric clinics but also the adult clinics by being an active employee. Hiring peer navigators will also demonstrate the clinics' commitment to the community, which will be important in continuing to establish trust. Importantly, if a peer navigator is to be hired, every effort should be made to ensure that they are an active member of the team to avoid tokenization and that systems are in place to address the cis-normativity in many medical systems hiring processes (gendered intake forms and approach to legal name versus name used by the employee) to ensure a safe working environment and retention.

7. Research

Out of the four outcome measures listed by Schmidt et al. (adherence to care monitoring, disease specific measures, patient-reported health and quality of life, and self-care), the three outcomes most relevant to TGE adolescents and young adults are adherence to care monitoring, patient reported health and quality of life, and self-care. There are no disease specific measures for gender affirming care, and TGE adolescents and young adults are often well informed on gender affirming medical care due to frequent need to educate their providers when accessing care [5]; therefore, health education and health literacy (in terms of gender care) may be less important for this group. For adherence to care monitoring, we recommend measuring attendance, not only gender related care, but also with non-gender related primary care appointments (well visits, illness related visits, etc.). These two attendance endpoints acknowledge the lack of a single standardized endpoint for transition and that medical care of TGE people extends beyond gender related care. Finally, it is vital to actively include community members, both TGE adolescents and young adults and adults, in the development and execution of any intervention, and to properly compensate them for their work [17, 25]. Without community involvement, there is a risk that important aspects of ToC for a particular community are missed, as the TGE community that each clinic serves is different. Additionally, including community members in active positions within the research team demonstrates commitment to growth and to the community [26].

8. Next Steps and Conclusion

To best address the health disparities faced by TGE individuals, healthcare can look within at the numerous structural barriers that TGE people must navigate to receive care [5, 21]. One substantial facet of those structural barriers is ToC, serving as a vulnerable time for our patients and a time when there is a substantial risk of loss to care due to the many changes occurring. As more TGE adolescents and young adults feel safe coming out, healthcare providers need to ensure that medicine is prepared to actively support and care for these adolescents and young adults throughout their lives. This involves ensuring that TGE adolescents and young adults are connected to compassionate primary care providers

with cultural humility and that this connection highlights the autonomy of TGE young adults and respects the vast expansive TGE experience.

We hope that this paper will help guide future research in ToC for TGE adolescents and young adults, and that it will help this research be informed by health equity and anti-racist perspectives. Without this foundation, any work approaching ToC will not be sustainable or beneficial to the community. We reemphasize the importance of bringing TGE people, especially TGE young adults, onto the research team to help ensure that this work is community centered. By fostering a seamless ToC from pediatric to adult care with a focus on health equity and within the frameworks discussed, we can contribute to reducing healthcare disparities and foster trust between medicine and the TGE community.

Conflict of Interest Disclosures

The authors declare that they have no competing interests.

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Abbreviations

Transition of care (TOC).
Transgender and gender expansive (TGE).

Contributors' Statement Page

Dr. Inwards-Breland conceptualized this perspective.
Dr. Karrington and Mr. Hamilton drafted the manuscript.
All authors reviewed and revised the manuscript and approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

References

[1] White PH, Cooley WC. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics.* 2018; 142 (5): e20182587.

[2] Schmidt A, Ilango SM, McManus MA, Rogers KK, White PH. Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of pediatric nursing.* 2020; 51: 92-107.

[3] Straus EJ, Brown HJ. The potential contribution of critical theories in healthcare transition research and practice. *Disability and Rehabilitation.* 2021; 43 (17): 2521-2529.

[4] Abramowitz J. Transgender medicine-transitioning transgender children to adulthood. *Reviews in Endocrine and Metabolic Disorders.* 2018; 19 (3): 227-230.

[5] James S, Herman J, Rankin S, Keisling M, Mottet L, Anafi Ma. The report of the 2015 US transgender survey. 2016.

[6] Turban JL, Keuroghlian AS. Dynamic gender presentations: Understanding transition and "de-transition" among transgender youth. 2018.

[7] Rider GN, McMorris BJ, Gower AL, Coleman E, Eisenberg ME. Health and care utilization of transgender and gender nonconforming youth: A population-based study. *Pediatrics.* 2018; 141 (3).

[8] Worthen MG. Hetero-cis–normativity and the gendering of transphobia. *International Journal of Transgenderism.* 2016; 17 (1): 31-57.

[9] Janeway H, Coli CJ. Emergency care for transgender and gender-diverse children and adolescents. *Pediatric emergency medicine practice.* 2020; 17 (9): 1-20.

[10] Jarvis SW, Roberts D, Flemming K, Richardson G, Fraser LK. Transition of children with life-limiting conditions to adult care and healthcare use: a systematic review. *Pediatric Research.* 2021: 1-12.

[11] Snorton CR. *Black on both sides: A racial history of trans identity.* U of Minnesota Press; 2017.

[12] Gill-Peterson J. *Histories of the transgender child.* U of Minnesota Press; 2018.

[13] Howard SD, Lee KL, Nathan AG, Wenger HC, Chin MH, Cook SC. Healthcare experiences of transgender people of color. *Journal of general internal medicine.* 2019; 34 (10): 2068-2074.

[14] Goldenberg T, Jadwin-Cakmak L, Popoff E, Reisner SL, Campbell BA, Harper GW. Stigma, gender affirmation, and primary healthcare use among Black transgender youth. *Journal of Adolescent Health.* 2019; 65 (4): 483-490.

[15] Power J, Gilmore B, Vallières F, Toomey E, Mannan H, McAuliffe E. Adapting health interventions for local fit when scaling-up: a realist review protocol. *BMJ Open.* 2019; 9 (1): e022084.

[16] Hoddinott P, Britten J, Pill R. Why do interventions work in some places and not others: a breastfeeding support group trial. *Soc Sci Med.* 2010; 70 (5): 769-778.

[17] Noonan EJ, Sawning S, Combs R, et al. Engaging the Transgender Community to Improve Medical Education and Prioritize Healthcare Initiatives. *Teaching and Learning in Medicine.* 2018; 30 (2): 119-132.

[18] Gonzalez R, Cameron C, Klendo L. *The therapeutic family model of care: An attachment and trauma informed approach to transitional planning.* Association of Childrens Welfare Agencies; 2012.

[19] Alpert A, Kamen C, Schabath MB, Hamel L, Seay J, Quinn GP. What Exactly Are We Measuring? Evaluating Sexual and Gender Minority Cultural Humility Training for Oncology Care Clinicians. *Journal of Clinical Oncology.* 2020; 38 (23): 2605-2609.

[20] Creating an LGBTQ-friendly practice. AMA. Population Care Web site. https://www.ama-assn.org/delivering-care/population-care/creating-lgbtq-friendly-practice. Published 2021. Accessed November 28, 2021, 2021.

[21] Inwards-Breland DJ, Karrington B, Sequeira GM. Access to Care for Transgender and Nonbinary Youth: Ponder This, Innumerable Barriers Exist. *JAMA pediatrics.* 2021; 175 (11): 1112-1114.

[22] Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People. In: MB Deutsch, ed. UCSF Transgender Care Department of Family and Community Medicine University of California San Francisco2016: transcare.ucsf.edu/guidelines.

[23] Reback CJ, Clark KA, Rünger D, Fehrenbacher AE. A Promising PrEP Navigation Intervention for Transgender Women and Men Who Have Sex with Men Experiencing Multiple Syndemic Health Disparities. *Journal of Community Health.* 2019; 44 (6): 1193-1203.

[24] Cunningham WE, Weiss RE, Nakazono T, et al. Effectiveness of a Peer Navigation Intervention to Sustain Viral Suppression Among HIV-Positive Men and Transgender Women Released From Jail. *JAMA Internal Medicine.* 2018; 178 (4): 542.

[25] Rosenberg S, Tilley PJM. 'A point of reference': the insider/outsider research staircase and transgender people's experiences of participating in trans-led research. *Qualitative Research.* 2020: 146879412096537.

[26] Brush BL, Mentz G, Jensen M, et al. Success in Long-Standing Community-Based Participatory Research (CBPR) Partnerships: A Scoping Literature Review. *Health Education & Behavior.* 2020; 47 (4): 556-568.