Commentary

Expanding Women's Health Practitioners and Researchers’ Understanding of Transgender/Nonbinary Health Issues

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Historically, American society has defined women’s health in contrast with men’s health and health care access in relation to gender-specific and/or sex-specific health needs (e.g., reproductive and sexual health needs), conditions, diseases and complications, and differences in the prevalence, severity, and courses of action to address those. The field of women’s health has traditionally included such topics as maternal health and pregnancy, human immunodeficiency virus/AIDS prevention and treatment, sexual and reproductive health care, mental health, nutrition, violence, cancer risk, and disabilities (World Health Organization, 2013). However, as the conversation around gender identity and expression continues to shift and evolve, the boundaries of “women’s health” have become fuzzier than they once were.

Transgender and nonbinary (TNB) individuals are often grouped together, yet they represent very distinct expressions of gender identity. Being trans generally refers to persons whose sense of personal identity and gender does not correspond with the sex assigned at their birth, such that there are trans men and trans women. Although nationally representative estimates do not exist, a recent study estimated that 390 adults per 100,000 U.S. adults, or almost 1 million adults nationally, identified as trans in 2016 (Meerwijk & Sevelius, 2017). Nonbinary (NB) people generally identify as a gender that is distinct from either male or female, or blends elements of being male or female, including but not limited to masculinity and femininity. They do not identify with any gender. Their gender can also be fluid and change over time. Among trans individuals, 25% to 35% reported that they were NB (American Psychological Association, 2015); no data exist on the prevalence of NB individuals who do not identify as trans (American Psychological Association, 2015). Because TNB people do not fit the traditional, socially constructed male/female dichotomy and because of the contrasting approaches to addressing women’s and men’s health issues, a key question arises regarding how best to address TNB health needs within the current constructs of women’s health.

If we define women’s health broadly as health issues related to women, then, certainly, we should include transgender women in this definition. Doing so allows women’s health conversations to include issues specific to transgender women, such as hormone replacement therapy as part of transitions, vaginoplasty, breast implants, interpersonal violence, and hate crimes against trans women, and transgender-related discrimination. Conversely, if we define women’s health more narrowly as sexual and reproductive health-related issues, then how are transgender men, transmasculine people, and NB individuals assigned female at birth included? Most require similar care as cisgender (non-transgender) women, including pap smears, sexually transmitted infection testing, and obstetrics and gynecology-related care. Neither of these definitions of women’s health includes all women, nor all individuals with vaginas, uteruses, and related female-associated anatomy. Moreover, by limiting women’s health to reproductive health issues, we also diminish the importance of other care besides care for reproductive health or organs for all women.

Research indicates women still have poorer overall health compared with men (World Health Organization, 2013), although research on gender and sexual minorities remains a challenge owing to sampling methodologies used in existing national surveys and small numbers more generally. No consensus currently exists on whether and how to include existing data, and thus the scientific community needs to develop analytical approaches and standards that do not lead to the automatic exclusion of
self-reported data on trans and NB status. In short, these narrow definitions and ways to view existing data deflect focus away from important, overarching needs for primary care providers, access to care, and mental health services, and from issues regarding gender-based discrimination.

This commentary does not aim to offer a perfect definition of women’s health. Rather, in this commentary we explore issues of health care experiences and needs regarding the TNB population, one often categorized under the umbrella of “women’s health” yet woefully underrepresented in data, research, and policies related to equitable health care provision and access. We argue for a more inclusive understanding of women’s health, which includes culturally responsive care for TNB patients.

Culturally Responsive Trans-Inclusive Health Care

Access and use of health care among TNB patients necessitates all types of care facilities throughout the United States and globally to implement culturally responsive care. Settings where TNB are least likely to access care (e.g., rural, international locations with anti-trans policies) may need to use unique implementation strategies (Knutson, Koch, Arthur, Mitchell, & Martyr, 2016). However, any health care facility can implement the essential evidence-based strategies outlined below. Minimally, the essential elements needed for a safe, inclusive, and affirming care facility include 1) training for staff and providers on the implementation of trans-specific standard of physical and mental care for patients at any life stage (e.g., child, adolescent, adult, older adult) and 2) an alteration of traditional care facility gender binary norms and the physical setting in which TNB patients seek care (Fenway Institute, 2018).

Although each TNB patient experiences unique physical and mental health needs, staff and providers of care must be trained on evidence-based standards of care for TNB patients (Fenway Institute, 2018). On a basic level, the training of staff and providers should initially include training on the use of gender-neutral language and providing inclusive questions on intake forms (i.e., assessment of one’s current gender, current anatomical structure, and sex assigned at birth) (Cahill & Makadon, 2014). These “first moments of contact” approaches to inclusive care are essential to reduce instances of delaying or postponing care (Center of Excellence for Transgender Health, 2016). Most important, providers should be trained on the unique physical and mental health needs of adult and child/adolescent TNB patients (e.g., hormone blockers, gender-affirming hormones, youth development, puberty suppression) (Center of Excellence for Transgender Health, 2016).

In terms of mental health, TNB patients often report increased rates of current depression, suicidal ideation, and suicide attempts owing to discrimination compared with cisgender individuals (Seelman et al., 2017). Thus, staff and providers should provide a safe environment that encourages discussion and care and/or referral for such mental health needs (Center of Excellence for Transgender Health, 2016). Every intake form should include an assessment of mental health concerns (e.g., primary mental health problems, environmental and social stressors, and gender-related needs) so as to allow for subsequent referrals that are appropriate for trans-affirming mental health services (Center of Excellence for Transgender Health, 2016). It is important to note that mental health concerns endorsed by a patient should not be automatically assumed to be related their gender identity (Center of Excellence for Transgender Health, 2016).

Currently, the University of California San Francisco’s Center of Excellence for Transgender Health and the Fenway Institute’s National LGBT Health Education Center offer evidence-based online resources for providing culturally appropriate and affirming care for TNB individuals. Resources from these organizations include educational programs and materials (e.g., health pamphlets; intake forms) on physical and mental health for adults and youth, consultations, and information for providers on how to improve the quality, access, and cost-effectiveness of trans-affirming care services.

Of additional importance to affirming and inclusive care settings is the actual physical setting where patients seek care. Safe, affirming, and inclusive facilities include an understanding of processes and procedures that integrate affirming and
inclusive care in a manner that improves the experiences of all patients (Fenway Institute, 2018). Specifically, the waiting room should include health pamphlets or other materials that show a commitment to TNB health issues (Center of Excellence for Transgender Health, 2016) and gender-inclusive restrooms should be easy to locate and accessible. Gender-inclusive restrooms are imperative to providing an affirming and safe space for all TNB individuals (National LGBT Health Education Center, 2015). Although trans-inclusive, evidence-based resources currently exist, this information is based on the minimal amount of TNB health data available. Next steps must include an intentional collection and analysis of representative data from TNB individuals of all ages and stages of transition.

Importance of Data: Existing Data Sources and Next Steps for Research

Physicians and other clinicians strive to make the best treatment decisions for their patients based on the best evidence and data available at that time. Although much more progress is still sorely needed, acknowledging the concerns and special needs of TNB patients has become more commonplace in the medical community. Alongside the growing literature on caring for TNB persons, anecdotal information has become more widely shared and has raised awareness about the special situations experienced by TNB persons in clinical (and other social) settings.

A recent review of the TNB literature found that most of the 2,000 articles included in the review consisted of case reports or case series, reviews, commentaries, editorials, letters, or ethics submissions (Wanta & Unger, 2017). The same review found that primary research was not as frequently published, and was limited to 1) cross-sectional, descriptive analyses in certain geographic areas of the country, 2) narrow epidemiological studies on prevalence, risk factors, and treatment of cancer and on incidence and treatment of human immunodeficiency virus, or 3) focused clinical trials on hormone therapy and metabolic outcomes in patients taking cross-sex hormones (Wanta & Unger, 2017). The authors of the review called for more research and for studies that would 1) be more nationally representative, 2) examine associations between sociodemographic factors and risk factors for certain conditions, particularly mental health and comorbid conditions, 3) determine the relationship between sociodemographic factors and access to, and use of, care and related outcomes, 4) rely on clinical trials to examine other treatments and outcomes of importance to transgender health and care, and/or 5) use longitudinal designs (Wanta & Unger, 2017).

Congress may consider a bill that proposes to add a gender identity question to the 2030 census. Although more than a decade off, this addition would allow for more nuanced research about the health and needs of the TNB population (Wang, 2018). State-focused, somewhat narrower analyses may be possible in the nearer term. Several years ago, Oregon adopted laws that enable residents to select a third gender other than male or female on their driver’s license and require public universities to allow all faculty, staff, and students to identify their gender identity and sexual orientation on any forms used to collect demographic data that include gender, race, or ethnicity. Colorado passed a policy allowing a third gender identification on driver’s licenses in 2018, and the state legislature in Maryland enacted a law in the 2019 legislative session that would provide a third gender selection on the driver’s license, with other states beginning to follow suit. Until then, there are a few extant national data sources, which could be further mined to refine clinicians’ competency in treating TNB patients.

The first is the National Transgender Discrimination Survey, a 70-item measure aimed at documenting the experiences of TNB persons in a number of key areas of life, including self-reported experiences in seeking health care (Grant et al., 2011). This one-time cross-sectional (primarily online) assessment resulted in 6,456 valid respondents from all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands (Grant et al., 2011). Although dated, this large dataset is publicly available and could be used to expand on descriptive analyses provided in the summary report published in 2011 (Grant et al., 2011).

The United States Transgender Health Survey was conducted in 2015 and included more than 300 questions across education, discrimination, health care, violence, housing, employment, and other social and health-related issues (James et al., 2016). Data were collected via a cross-sectional design in the same locations as the National Transgender Discrimination Survey, and extensively used community partnerships in an effort to oversample TNB people of color, older TNB individuals, TNB people with disabilities, and those living in rural settings. With a sample size of 27,715, this dataset of TNB individuals is the largest known publicly available resource. A multitude of community reports, including state by state profiles, have been published, but scientific studies are still needed (James et al., 2016).

The nationally representative Behavioral Risk Factor Surveillance System, managed by the Centers for Disease Control and Prevention since 1984, tracks health-related risk behaviors, chronic health conditions, and use of preventive services (Centers for Disease Control and Prevention, 2018). In some states, it includes a question assessing TNB identity status that could be used to stratify samples for comparing TNB to cisgender respondents or to factor into multivariate analyses (The question reads as follows: “Do you consider yourself to be transgender? (If yes, ask “Do you consider yourself to be male-to-female, female-to-male, or gender non-conforming?”) Possible answers include: “Yes, Transgender, male-to-female; Yes, Transgender, female to male; Yes, Transgender, gender nonconforming; No; Don’t know/Not Sure; Refused; BLANK Not asked or Missing.”). Although the Behavioral Risk Factor Surveillance System is regarded as one of the main epidemiological surveys in the United States, has been in place for many years, and is publicly available, it has limitations. For one, it is not powered or does not oversample for TNB persons, which can make sophisticated statistical analyses challenging, especially when the interest is in state-level analyses. In addition, questions do change fairly regularly, making it difficult to move beyond cross-sectional analysis owing to comparability issues. Finally, not all states participate, and there is the potential for the gender module to be discontinued (Lewis, 2018).

Despite the limitations highlighted for these datasets, they are among the largest sources currently available today. Researchers and others can and should use these sources more often to increase the generation of new knowledge on TNB health and care, and to help improve clinical decision making as well as provide the evidence base needed by policymakers to make the most informed decisions.

Recommendations

Based on the analysis provided in this commentary, we make the following recommendations for researchers,
managers of facilities and health care organizations, and practitioners.

- Include in research studies the assessment of health issues beyond the traditional umbrella of "women's health" so that evidence-based resources can be developed and implemented.
- Provide access to these resources to a wide range of health care providers, including women's health care providers, in addition to providers who are already devoted to an inclusive practice.
- Share data with policymakers so that they can make the best possible decisions affecting TNB health.
- Modify the definition of "women's health" to include transgender women, transgender men, other transmasculine individuals, NB individuals, and others whose experiences with gender-related health disparities mirror those traditionally impacting cisgender women. Moving toward a more inclusive understanding of women's health allows the focus to remain on issues of gender-based differences and includes all affected.
- Implement processes and procedures for providing evidence-based trans-inclusive care at the facility level to reduce instances when TNB persons will avoid seeking care.
- Train all staff (including but not limited to providers) on TNB health issues.
- Provide physical environments that are visibly safe, affirming, and inclusive.
- Deliver culturally responsive and inclusive TNB health care, thereby improving the quality of clinical practice.

We designed these eight recommendations for researchers, practitioners, health care organizations and facilities, and those who manage them and others with an interest in TNB issues to improve our common understanding of TNB health needs and how to better address them as a society and as a health care system. Although evidence-based trainings and other resources for providing trans-inclusive care are available for providers and facilities, this information is based on a minimal amount of TNB health research. Currently, three large publicly available datasets provide the bulk of data for understanding TNB health. However, each is limited by cross-sectional study designs, and the assessment of health issues traditionally defined as "women's health issues." With only these data, we do not yet have the ability to make representative conclusions about the unique health needs of TNB patients. In the meantime, our recommendations can support health care staff and providers in the delivery of gender-sensitive care to TNB individuals while improving data collection and research documenting the needs of these underserved populations and the services they receive.

References


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