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The Editor's Introduction

As you read the following article, I ask that you think outside the box with the lesbian, gay, bisexual, and transgender relevance to life care planning. Our job is to be sensitive to the cultural needs and how they impact the rehabilitation process. Life care planners ask what sex the evaluee is, but have you asked what sex they were at birth and what sex they are currently at the time of the life care plan? You might be thinking, but I'll never have a case like this. Well, I have, and that defines an entire different problem of possibilities of how to approach the life care plan regarding pre-existing needs and what is to be included in it. Please read this article with an open mind.

Lesbian, Gay, Bisexual, and Transgender Population; Ensuring Cultural Competency for the Transgender Population When Developing a Life Care Plan

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Abstract

As lesbian, gay, bisexual, and transgender (LGBT) individuals become more socially recognized, there remain significant challenges that impact their healthcare and well-being. Societal stigmas, economic discrimination, safety violations, and breaches of civil rights have resulted in negative health outcomes for this population. Rehabilitation and healthcare professionals need to understand the disparities of this marginalized population when developing a life care plan. This article serves as an overview so that professionals can help address some of these challenges and to better promote cultural competency within the profession.

Lesbian, Gay, Bisexual, and Transgender Population; Ensuring Cultural Competency for the Transgender Population When Developing a Life Care Plan

As lesbian, gay, bisexual, and transgender (LGBT) individuals gain more acceptance into society, healthcare professionals, too, must accept LGBT patients and be trained to appropriately and sensitively address them and their unique concerns. "LGBT" is a term that groups together lesbian, gay, bisexual, and transgender individuals; however, one individual who falls into this group may differ greatly from another LGBT individual. Each has his or her own distinct traits and nuances. As LGBT individuals become more socially recognized, there still remain significant challenges. Societal stigmas continue to exist and are related to health disparities, economic discrimination, safety violations, and breaches of civil and human rights, with transgender individuals having the most substantial challenges of all the LGBT groups (Parkhill, Mathews, Fearing, & Gainsburg, 2014).

"Transgender" is a term used to describe individuals whose gender identity (and/or gender expression) differs from the sex assigned at birth. Gender identity refers to a person's internal sense of self (i.e., being male or female). This differs from sexual orientation, which is a person's sexual preference or identity as bisexual, heterosexual, or homosexual (Merriam-Webster, n.d.). For transgender individuals, the sex they were assigned at birth and their own internal gender identity do not match and do not conform to societal norms (Mayer et al., 2008). Transgender identities can also exist on a continuum and may include individuals who refer to themselves as "genderqueer," not identifying as either man or woman, male or female; or "gender-nonconforming," having gender identity or expression that differs from sex assigned at birth and does not fit traditional or societal expectations (World Professional Association for Transgender Health, 2011). Case and Ramachandran (2012) describe the spectrum of ambiguously defined sexual identities as "bigender," a sub-category of transgenderism, describing individuals who experience a blending or alternation of gender states.

There are many terms used to represent an individual who does not ascribe to the binary gender system, male and female. A transgender man is a person whose sex assigned at birth is female but whose gender identity is male (also known as FTM, female to male, trans man), and a transgender woman is the reverse (also known as MTF, male to female) (National Center for Transgender Equality, 2014).

Gender incongruity dates back to biblical times with documentation of cross-dressing, but it was not until the mid-twentieth century that it came to light in western society (Ettner, Monstrey, & Coleman, 2016). Sexual reassignment surgery was reported in Germany as early as 1930. In 1952, gender incongruity came under attack after a United States citizen underwent hormone replacement therapy and a series of operations for gender reassignment surgery in Denmark, known as the *Christine Operation*. This drew worldwide attention and stirred much legal, religious and moral controversy and further research. Doctors and researchers developed psychoanalytical, environmental, and biological theories in an attempt to explain gender incongruence (Ettner, Monstrey, & Coleman, 2016).

In 1995, anatomical post-mortem studies were reported; and by 2008, the focus shifted to hormones, genes, and cephalic structure, providing the foundation of a neurodevelopmental theory of gender formation (Ettner et al., 2016). In 2011, the Institute of Medicine released a report on the health status of lesbian, gay, bisexual, and transgender populations. Their findings confirmed health disparities found within this population. The report identified the transgender community has having specific health issues that need further research in the areas of prevalence, defining who should be considered transgender, and the demographic characteristics of this population (Ettner et al., 2016; Institute of Medicine, 2011).

The number of LGBT individuals living in the United States (U.S.) is not accurate due to lack of sexual orientation and/or gender identity questions, but research by Gates (2011) indicated that 3.5% of adults living in the U.S., or approximately 9 million, identified as LGBT. Whereas recent population-based statistics have estimated approximately 950,000 individuals living in the U.S. identify as transgender (Conron, Scott, Stowell, & Landers, 2012; Gates, 2011), however, this estimate may be imprecise. The incidence of LGBT Americans is likely underreported due to many factors, but at least one is the fact that few national surveys ask about gender identity. Other limitations include varying definitions, survey methodology, and small sample size (Gates, Mottet, & Tanis, 2010; Gates, 2011; Meier & Labuski, 2013).

Underreporting of LGBT status has also been associated with a fear of discrimination, and its repercussions, due to their gender nonconformity. A review of U.S. data concluded transgender individuals experience significant violence throughout their lifespan, including emotional, physical and sexual abuse (Brown & Herman, 2015). These acts of violence are from strangers, acquaintances, and even family members (Stotzer, 2009).

Recent research data has helped to identify the challenges faced by transgender groups, particularly as it relates to the effects of social, medical, and economic marginalization. Lack of appropriate provider training is linked to higher incidence of mental health issues, HIV infection, and drug, alcohol and tobacco use (Bockting et al., 2013; Grant, Mottet, Harrison, Herman, & Keisling, 2011; Healthy People 2020). The National Transgender Discrimination Survey (NTDS) conducted by the National Gay and Lesbian Task Force and National Center for Transgender Equality, concluded that 41% of survey participants reported suicide attempts, as compared to the 4.6% of the general U.S. population and the 10-20% of lesbian, gay, and bisexual (LGB) groups (Haas, Rodgers, & Herman, 2014).

Healthcare disparities in the transgender population are of significant concern because they have been proven to result in negative health outcomes when compared to the health of their heterosexual counterparts (Institute of Medicine, 2011). Research has reported that transgender individuals have a high incidence of HIV, sexually transmitted diseases (STD), mental health disorders and even suicide (Healthy People 2020, 2011).

Transgender individuals encounter significant barriers when trying to access services. Besides the lack of healthcare providers who are knowledgeable about transgender health, there are also documented accounts of transgender individuals being denied care because of their transgender status (Fredriksen-Goldsen et al., 2014; Haas et al., 2014; Xavier et al., 2013). There is a wide range of discrimination reported by transgender individuals ranging from verbal harassment and violent behavior to medical treatment refusal (Grant et al., 2011). In the NTDS, the rate of treatment refusal by healthcare providers was 60% (Haas et al, 2014). This blatant discrimination may cause transgender people to avoid health screenings and necessary medical treatments, thus creating significant health disparities (Grant et al., 2011).

Transgender people also face economic forms of discrimination. Bradford, Reisner, Honnold, and Xavier (2013) found that 41% of transgender research participants reported experiencing some form of discrimination related to healthcare, housing, education and/or employment. Transgender individuals have a higher incidence of poverty and of being uninsured (Grant et al., 2011).

There are treatment options available to help transgender individuals manage gender dysphoria, the distress individuals feel when there is a disconnect between their gender identity and the sex that is assigned at birth (Knudson, De Cuypere, & Bockting, 2010; U.S. National Library of Medicine, 2016). "Transitioning," the term used to describe the process of affirming one's gender identity, does not always involve medical interventions. This process can include voice training, use of preferred names and pronouns, gender-appropriate clothing and mannerisms, and exercises that accentuate certain body parts (Erickson-Schroth, 2014).

Some transgender individuals undergo hormone replacement therapy (HRT) to enhance characteristics of their gender identity or to suppress those that are the result of their assigned gender. This requires a close relationship with a provider who has knowledge of hormone prescribing and other transgender health concerns (Knezevich, Viereck, & Drincic, 2012). This can be problematic because LGBT-specific education is limited in most medical and nursing curriculums (Institute of Medicine, 2011; Obedin-Maliver et al., 2011).

Another possible option to help transgender individuals reduce gender dysphoria is sex-reassignment surgery, including gender-affirming surgery, gender-reassignment surgery, and gender-confirming surgery. Male-to-female gender-reassignment surgery includes gonadectomy, remodeling of the male external genitalia to create female external genitalia with reconstruction of the urethral meatus and a sensate clitoris, and creation and lining of a neovaginal

cavity. Female-to-male surgery can involve bilateral mastectomy, hysterectomy, and bilateral salpingo-oophorectomy. Some surgeries involve implants and prostheses that help transgender individuals better connect to their gender identity (Unger, 2014). It is often presumed that all transgender individuals want reassignment surgery; however, it is not a universal desire. Because not all transgender individuals require hormones or surgery, treatment is a very individualized decision and one that must best suit the individual's specific needs (Murad et al., 2010).

Morrison et al. (2016) surveyed 322 plastic surgery residents and fellows from various training programs across the United States. Sixty-four percent of the respondents reported direct or indirect exposure to patients who were transgender during their residency. More than half were exposed to some type of gender-confirming surgery (GCS). Overall, the respondents confirmed the need for more education and training, addressing the healthcare needs of the transgender population, with 72% of the respondents advocating for GCS fellowship training opportunities (Morrison et al., 2016).

A large percentage of health insurance providers in the U.S. do not cover gender-reassignment surgeries, creating a substantial financial burden for transgender individuals. Some health insurance companies also deny coverage for care that does not match the gender of record, for example, refusing to provide coverage if a transgender woman (a person whose sex assigned at birth was male and then legally changed his records to gender female) develops prostate cancer (Robinson, 2010). However, governmental policies and legal challenges are underway to remove barriers of inequality that have been imposed upon the LGBT community.

Healthy People, a governmental agency whose goal is to improve the health of the nation by setting goals and objectives which are updated every ten years, formed the *LGBT Issues Coordinating Committee*. This committee added a new goal specific to the LGBT population in the U.S. for Healthy People 2020: "Improve the health, safety, and well-being of lesbian, gay, bisexual, and transgender (LGBT) individuals" (www.healthypeople.gov). From this initiative, others have been formed including the *LGBT Health Outcomes Planning Project* (HOPP). HOPP and other project participants developed goals specific to the LGBT population which included access to health, community engagement, LGBT policy, and LGBT-related data. This broadens the focus on health disparities affecting the LGBT population and expands the network of community agencies committing to improve the health, safety and well-being of this population (www.healthypeople.gov).

The Affordable Care Act (ACA) includes preventive services for HIV and STD screening, immunizations, and other chronic disease screenings which benefit the LGBT community (www.hhs.gov). Section 1557 of the ACA prohibits discrimination based on sex, including gender identification and stereotypes, in any health program receiving federal funds. The ACA calls for improved data collection for routine data surveillance on health disparities. As a result, sexual orientation and gender identity (SOGI) questions were added to the National Health Interview Survey (NHIS) which, since 1957, has tracked the nation's health status, healthcare access, and progress toward achieving national health objectives. The Behavioral Risk Factor Surveillance System (BRFSS) since 1984 has collected state-specific data from U.S. residents regarding health-related risk behaviors, chronic health conditions, and use of preventive services. In 2015 the addition of SOGI data was included in the Meaningful Use of Electronic Health Records program (Ranji, Beamesderfer, Kates, & Salganicoff, 2014).

Health insurers who continue to provide plans with discriminatory exclusion affect the health and well-being of the transgender population (Cray & Baker, 2012). Depending upon a person's transitional status, HRT usage to enhance or suppress characteristics of the preferred gender identity or gender reassignment surgery, a transgender person may require a combination of healthcare services such as Pap smears, prostate examinations, and mammography. Preventive screenings, wellness care, emergency services, etc., should be accessible to all policyholders and without transgender-specific exclusions (Cray & Baker, 2012). By making preventative screenings, wellness care, emergency services, etc. available to the transgender population, it has the potential to reduce the burden on medical care costs.

The transgender population does not fit in the binary gender system of male and female classification. Alternative gender designations allow individuals to express their true sense of self. Many countries, such as India, Nepal, and Australia, provide other gender options, such as "T" for transgender or "O" for other, while the U.S. still requires the binary system of gender identification be used on all official documents (Kutner, 2015). The Health Resources and Services Administration (HERSA) acknowledge sexual orientation and gender identity are significant in determining healthcare outcomes. In 2016, HERSA changed its data collection requirements to include LGBT population to increase its understanding of the specific care required to better promote cultural competency (HERSA, 2016). Rehabilitation and healthcare professionals need to expand the assessment process and include the LGBT and transgender community.

Life care planners practice in a variety of settings including health, disability and workers' compensation insurance, special needs trusts, case management, and senior care (Nurse Life Care Planning, 2015). When developing a plan, the illness or disability takes center stage, but the

rehabilitation and healthcare professionals must demonstrate inclusivity in conjunction with any factors that may have a potential impact on the illness or disability.

Life care planners must understand the healthcare needs of a transgender evaluee. Factors that may influence the development of a life care plan include sexual identity. Cross-sex hormone therapy (CSHT), although considered "off-label," is used for feminizing and masculinizing purposes. Side effects of these drugs and complications of prolonged use may impact the overall health of an individual and may affect ongoing care and services to be included in a life care plan (Fenway Institution, 2015). Studies have reported the use of these hormones possibly affect multiple body systems and can cause disruption in health (Fenway Institution, 2015). Persons with psychiatric disorders may experience a disruption in their disease management, demonstrating various disorders, including bipolar, schizophrenia, and schizoaffective sequelae. Other health implications may include thromboembolic events, diabetes, insulin resistance, hepatotoxicity, polycythemia, and sleep apnea, depending on the hormones that are used; estrogen, anti-androgens and testosterone (Fenway Institution, 2015). In contrast, Weinand and Safere (2015) on transgender individuals taking hormone therapy, concluded the risks associated with CSHT are low, but additional research is needed involving larger cohorts and more long-term studies.

Discussing sexual orientation with an evaluee is a sensitive topic, and additional training for effective communication, patient privacy and confidentiality may be necessary (Fenway Institution, 2016). Rehabilitation and healthcare professionals who demonstrate more gender-sensitive skills will better understand and address the needs of the LGBT population. Asking the evaluee about sexual orientation and gender identity will produce a more client-specific plan relevant to that evaluee.

Since members of the LGBT community may hide their sexual identity due to fears of discrimination and stigma, it is important to ensure a safe and welcoming environment by ensuring confidentiality when asking sexual orientation or gender-specific questions (Fredriksen-Goldsen, et al., 2011). Within the LGBT community, "family" may be defined differently due to abandonment based on sexual identity. It is important to allow the evaluees an opportunity to discuss their view of family by using open-ended questions, such as "Who is important in your life?" or "Who is your family of choice versus origin?" Friends often are the caregivers in the LGBT community as opposed to the general population whose caregivers are typically related to them by birth or marriage (Fredriksen-Goldsen et al., 2011). However, it is important to note that within the role of creating a life care plan in the context of litigation, confidentiality may not be possible. At this point, the life care planner may need to involve a referral to a counselor who can provide confidentiality and a comfort level, with the possibility of the life care plan not being confidential.

When exploring services for the LGBT community, ensure the providers, agencies and organizations respect inclusion and reflect diversity. Cultural diversity should be promoted through competency training for all staff members. Establishments should display visible insignia which signifies unity and tolerance, such as a rainbow-colored flag, transgender pride flag, gender fluid flag, or a SafeZone symbol.

Implications for Life Care Planning

Cultural competencies are a foundational pillar which allows the rehabilitation and healthcare professional to practice without bias and marginalization of groups, including the LGBT community, especially the transgender population (Agency for Healthcare Research and Quality, 2014). Changes at the professional level need to focus on knowledge, attitudes, and skills when interacting with the evaluee and their family. Principles that guide rehabilitation and healthcare professionals make them accountable for judgment and decisions based on best practices steeped in evidence. Standards of practice for life care planning include cultural factors that may influence the plan and a code of conduct that prohibits discrimination against any person, including gender and sexual orientation (Nurse Life Care Planning, 2015; International Academy of Life Care Planners, 2015).

Professionals and organizations that serve the LGBT community should value diversity and be aware of and familiarized with its cultural context. Interventions to promote cultural competencies may include knowledge programs that use a universal approach involving reflective awareness, empathy, active listening techniques, and thoughtful experiences that may have contributed to cultural insensitivity (Agency for Healthcare Research and Quality, 2014).

It is apparent that more research and education need to occur in order to service this population more effectively, thereby truly representing the evaluee when we write a life care plan.

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