

**TRANSGENDER HEALTH: SENSITIVITY
IN CARE, TREATMENT, AND LIFE CARE
CONSIDERATIONS**

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10/31/2019-11/02/2019

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**POEM: WHAT IT FEELS LIKE TO FINALLY
ARRIVE YET BE ALONE**

Please listen respectfully to this person's cry for help and understanding from a society that does not see them as deserving of respect or recognition.

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OBJECTIVES

- Understand the unique needs for provision of services to people who identify as transgender
- Learn proper terminology for addressing and serving people who identify as transgender
- Learn the monetary cost of transition from gender of birth
- Understand the emotional cost of identifying as transgender

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TRANSGENDER: AN EVOLVING TERM AND DIAGNOSIS

- Once viewed as a mental illness or a psychopathologic entity (1950s). There is stigma attached to mental illness.
- Diagnostic and Statistical Manual of Mental Disorders (DSM-V) now uses term gender dysmorphia.
- Evidence now is more in support as this being a biologic based phenomenon (Muehler & Filizaitis, 2017)

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YET THE STIGMA & DISCRIMINATION CONTINUES

From Family & Friends

- Conversion Therapy as a means to get rid of the urges to be another gender than what one was born (Nichols, 2016)

From Public & Private Sectors

- Occurs in Health and Non-health settings

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DISCRIMINATION IN RECEIVING SERVICES

"A survey found that...
 26.25% of individuals who identify as transgender delayed preventative care due to fear of discrimination.
 23.98%-46.66% reported past experiences of overall discrimination in the forms of service denial, verbal harassment, or physical assault" (Glick, Theall, Andriopoulos, & Kendall, 2018)

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TRANSGENDER PEOPLE LIVE GLOBALLY

Approximately 1.4% of people worldwide have been diagnosed with gender dysphoria as it is defined within the DSM-V.

(Zurdo et al., 2018)

Seven horizontal lines for notes.

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ESTIMATED NUMBER IN THE USA

People who identify as transgender are a growing population within our society. Current estimates place the number of individuals identifying as transgender in the United States as 1.4 million.

(Flores, Herman, Gates, & Brown, 2016)

Seven horizontal lines for notes.

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THE TRANSGENDER POPULATION

The True Number is Unknown

- Williams Institute, based on information from the 2014 from Behavioral Risk Factor Surveillance System (BFRSS)
- 1.4 million or 0.6% of US adults identify as transgender
- Extrapolated to world population = 25 million total transgender people

(Meagher & Filmer, 2017)

Seven horizontal lines for notes.

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WHY IS THE TRUE NUMBER NOT KNOWN?

- National population based surveys rarely include questions that are inclusive to this population (Meagher & Filmer, 2017)
- Many people with gender dysphoria do not seek medical care (Meagher & Filmer, 2017)
- Many do not reveal that they identify as transgender due to fear of discrimination (Golden & Oransky, 2019)
- Fear of losing jobs (Grant et al., 2011)
- Fear of losing housing or homelessness
- Fear of poverty (Zevin, 2017)

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MANY PEOPLE WHO IDENTIFY AS TRANSGENDER ARE OFF THE GRID: 2' STIGMA, POVERTY, SHAME

- There are state laws put into place that actually work against people who are in the LGBTQ community; legal protections are limited (Turner, 2018)
- Barriers to advocacy for those who are partners to transgender individuals (Marock & Stephenson, 2018)
- Governmental agencies such as the VA discriminate against LGBTQ Women veterans (Shepherd, Darling, Klip, Rose, & Yano, 2018)
- Direct discriminatory practices and removal of Obama-era protections for transgender students (Golden & Oransky, 2019)

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YET PEOPLE WHO IDENTIFY AS TRANSGENDER HAVE SPECIAL NEEDS

When Considering Life Care Planning It is Vital to Understand

- Pathophysiology
- Diagnosis
- Treatment
- Co-morbidities
- Long-term mortality

(Meagher & Filmer, 2017)

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PATHOPHYSIOLOGY: THE PURSUIT IS NOT W/O COMPLICATIONS

- Hypertriglyceridemia (2° estrogen)
- Hyperprolactinemia (2° estrogen)
- Liver dysfunction (2° testosterone)
- Hypertension (2° testosterone) (Meagher & Filmer, 2017)
- Post-Surgical Complications are common: Vesicovagina fistula, urinary incontinence (de Toledo, de Jesus, Moreira, & de Almeida Toni, 2018; Meagher & Filmer, 2017)

* Not an inclusive list

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DSM-V DIAGNOSIS: GENDER DYSPHORIA
(DSM-5, 2013)

A marked incongruence between one's experienced/expressed gender and a signed gender, of at least six months duration plus at least two of the following

- Strong desire to be of the other gender
- Strong desire for the primary and/or secondary sex characteristics of the other gender
- Strong desire to be rid of one's primary and/or secondary sex characteristics
- Furthermore, there should be clinically significant distress or impairment in social, occupational, or other important areas of functioning

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CO-MORBIDITY: PSYCHIATRIC IS MAJOR
(KAGLÉ, SAWAN-GARCIA, & FIREK, 2017)

- Depressive symptoms
- Life-time Suicidality Attempt Risk (Haas, Rodgers, & Herman, 2014)
 - 46% transmen
 - 42% transwomen
 - 44% female assigned cross dressers
 - 21% male assigned cross dressers
- Interpersonal trauma exposure
- Anxiety
- General distress

Many of the psychiatric issues have been attributed to social stressors to include bias events, discrimination and stigma, lack of social support or community connectedness with the lack of effective coping strategies (Haas, Rodgers, & Herman, 2014; Valentine & Shipherd, 2018)

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LONG-TERM MORBIDITY & MORTALITY

- Suicide*
- AIDS
- Ischemic heart disease
- Illicit drug abuse
- Lung and hematological cancers (MtF group)

**It should be noted that suicide is the most common cause of death (cardiovascular causes of death were slightly increased and malignancies were more common, but did not reach statistical significance) (Meagher & Filmer, 2017)*

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LIFE CARE CONSIDERATIONS

Life care planners are in a distinctive position to provide their specialized services to a formally under-recognized and under-supported population. What was normally considered a small population has now come forward as more Millennials report identifying as Lesbian, Bisexual, Gay, Transgender or Queer (LGBTQ).

A 2017 study revealed that 20% of millennials identify as LGBTQ (GLAAD, 2017). People who identify as transgender are predicted to grow as those who identify begin to come forward (Rider et al., 2018; Schwartz, 2018)*

*an excerpt from Transgender Health: Sensitivity in Care, Treatment, and Life Care Considerations for Female to Male Transgender Individuals, JGCP (in press)

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SELF-EDUCATE... THIS IS AN EVOLVING AREA OF PRACTICE.

Many people who identify as transgender are too often burdened with the expectation that they must educate their healthcare providers while remaining steadfast in the face of discrimination (Vernier, Jackson, & Marshall, 2018)

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A CASE STUDY

Jeremy is 15. He was born male, but identifies as female. He has been not wanting to go to school and has had difficulty sleeping. He has trouble paying attention in school and at home. His grades have been dropping and he has quit playing baseball. He has begun to wear his sister's clothes and has changed his name to Sally. He is crying and says he wants to kill himself. Jeremy's parents have begun to take him for counseling. He has increasingly been expressing the need to express himself as female in the home. This expression began at age 13 and has been increasing exponentially.

Sally meets the criteria for gender dysphoria. She has become a client for an interdisciplinary approach for transitioning to female.

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TREATMENT

- Involves a 5 phase process
- The final phase is sex reassignment surgery

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TRANSITIONING: THE 5 PHASES

- Diagnosis
- Counseling
- Real-life experience (3-12 months)
- Hormone therapy*
- Sex reassignment surgery

*The effects of feminizing occurs within a few months and continue for 2-3 years before plateauing. (Mugher & Filmaier, 2017)

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WHAT CAN SALLY & HER FAMILY EXPECT?

- Discrimination and Stigma Yet, Better Quality of Life
- Better Quality of Life (QOL)
- High Cost for transition (monetary and socially)

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DISCRIMINATION AND STIGMA

Discrimination and Stigma Depending on the State

Fifteen states currently offer no specific legal protections for the LGBT population, and another 21 states only offer partial protections (MAR, 2018)

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QOL

Better Quality of Life (QOL)

"In a systematic review of 28 studies and 1833 transgender individuals who underwent gender reassignment (hormone therapy with or without sex-reassignment surgery), 80% of individuals reported improvement of gender dysphoria, 78% reported improvement in psychological symptoms, and 80% reported improvement in quality of life" (Meagher & Filmer, 2017, p. 46)

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YET! QOL IS TIED TO SOCIETY'S VIEW OF THE PERSON'S GENDER

"It will be noted that questions about our gender are in essence questions about who we are as persons, and thus being ashamed about our gender is also an attack on our status as persons. Gender is an intimate and private matter, and at the same time it has an obvious public dimension"

(Giordano, 2018, p. 2)

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SHAME

... shame is a social issue, not just a psychological issue. This means that in order to address shame, and to prevent the harms associated with it, it is not sufficient to work with individuals within a clinical setting: it is necessary to also reflect and address, with appropriate social and public policy interventions, the social determinants of shame..."

(Giordano, 2018, p. 3)

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COMMUNICATION & THE NEED FOR SENSITIVITY

- Use proper terminology in public. Be an educator to others.
- Use the name AND pronoun they wish to be called.
- If they are transitioning, ask what they wish to be called in public (Inabrock, 2015)

This is more than Simply Courtesy!

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SOBERING SUICIDE STATISTICS

Study by the American Academy of Pediatrics

- >50% of transgender male teens who participated in the survey reported attempting suicide in their lifetime
- ≈ 30% of transgender female teens said they attempted suicide
- ≈ 42% of non-binary youth respondents stated that they had attempted suicide at some point in their lives (Hassanain, 2018)

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DISCLOSURE IS TIED TO SUICIDE

“Prevalence of suicide attempts is elevated among those who disclose to everyone that they are transgender or gender-non-conforming (50%) and among those that report others can tell always (42%) or most of the time (45%) that they are transgender or gender non-conforming even if they don't tell them”³⁷ (Hans, Rodgers & Herman, 2014, p.2)

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TERMINOLOGY: BEGINS BY ASKING

- Transgender is the correct term to use versus transsexual or transgendered.
 - Avoid using the term transvestite.
 - Intersex is preferred to hermaphrodite.
- (Imberock, 2015)

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BEST PRACTICE

- Life Care Planners need to be sensitive and understanding when planning
- This can only be accomplished if they are self-aware and self-educate
- This means reading evidence-based material while
- Hearing the needs of their individual clients (Shuster, 2019)
- There is misinformation in the public sector; many people who identify as transgender use the internet and are misdirected by those who are like themselves or who hope to gain from desperate people (personal communication J. S. 2018; a MF individual who is transgender)

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ASSUMPTIONS IN CARE: DON'T

Instead Ask

- What is needed
- What is desired
- What is hoped for
- What is reasonable

Many people who identify as transgender feel alone in this journey and need guidance; they are used to health disparities (Valentine & Shepherd, 2018)

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INFORMED CONSENT

- Many providers say they follow informed consent, but *fail* to practice it
- A recent study, by Shuster (2019) found that providers revert to a paternalistic model of care when caring for trans populations
- Paternalistic Models shift the power differential and decision-making

(Shuster, 2019)

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HEALTHCARE ORGANIZATIONS HAVE A DUTY

“Although clinicians may self-report that they are familiar with LGBT health issues, gaps in practice and knowledge indicate the need for more training, especially in transgender health and in talking to patients about sexual orientation and gender identity.

Healthcare organizations also need support in ensuring that their organizations create inclusive environments by educating staff and leadership on nondiscrimination policies”

(Goldhammer, Minton, Kinock, Davis, & Kouroughian, 2018, p. 461)

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LASTLY

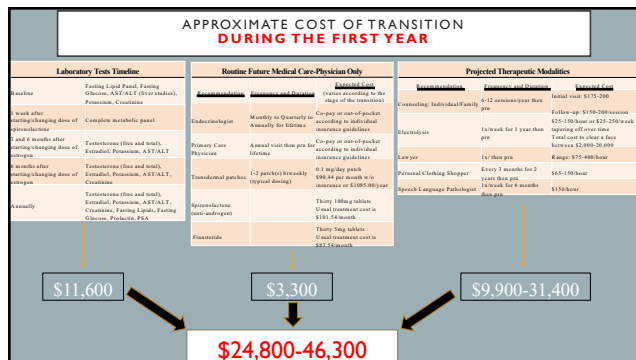
Transgender Health Care is an Evolving Field of Medicine

As an example, in relation to laboratory studies, “Transgender appropriate reference interval studies are virtually absent within the medical literature and should be explored” (Goldstein, Corneli, & Greene, 2017, p. 1342)

Gaps in literature are evident when performing health-related literature reviews. Many studies have data, but are observational in nature, therefore not as reliable as noted by Meagher and Filzmaier (2017).

LCPs can get in on the ground floor for provision of services

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COST OF HEALTH CARE

See Poster 1

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THE COST OF ANCILLARY SERVICES

See Poster 2

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QUESTIONS???

Life Care Planners are in a unique position to help people who identify as transgender to make safe and reasonable choices for best outcomes.

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REFERENCES

- American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5). Arlington, VA: American Psychiatric Association, 2013.
- de Toledo, L.G.M., de Jesus, R., Moreira, & de Almeida Tosi, L. (2018). Transcervical repair of vesicovaginal fistula in female transsexuals. *International Urogynecology Journal*, 29(9), 1407-1409. <http://dx.doi.org/10.1007/s00192-018-3670-y>
- Flores, A.R., Herman, J.L., Gates, G.J., & Brown, T.N.T. (2016). How many adults identify as transgender within the United States. *The Williams Institute: UCLA School of Law*. Retrieved from <http://www.williamsinstitute.law.ucla.edu>
- Giordano, S. (2018). Understanding the emotion of shame in transgender individuals – some insight from Kafka. *Light Sciences, Society and Policy*, 1(41). <https://doi.org/10.1186/s40504-018-0085-y>

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REFERENCES

- Golden, R.L., & Ormsky, M. (2019). An intersectional approach to therapy with transgender adolescents and their families. *Archives of Sexual Behavior*. <http://dx.doi.org/10.1007/s10508-018-1354-9>
- Goldhammer, H., Maston, E. D., Kissack, L. A., Davis, J. A., & Kruppelham, A. S. (2018). National Findings from an LGBT Healthcare Organizational Needs Assessment. *LGBT Health*, 5(3), 461-468. <http://dx.doi.org/10.1089/lgbt.2018.0118>
- Goldstein, Z., Council, T.A., & Greene, D.N. (2017). When gender identity doesn't equal sex recorded at birth: The role of laboratory in providing effective health care to the transgender community. *American Association for Clinical Chemistry*, 63(8), 1342-1352. <http://dx.doi.org/10.1373/clinchem.2016.258780>
- Glick, J.L., Theall, K.P., Andriopoulos, K.M., & Kendall, C. (2018). The role of discrimination and care postponement among trans-feminine individuals in the US national transgender discrimination survey. *LGBT Health*, 5(3), 171-179. <http://dx.doi.org/10.1089/lgbt.2017.0093>
- Grant, J.M., Mottet, L.A., Tanis, J., Harrison, J., Herman, J., & Keisling, M. (2011). Injustice at every turn: A report of the national transgender discrimination survey (PDF). National Center for Transgender Equality and National Gay and Lesbian Task Force. Retrieved from http://www.thetaskforce.org/static_html/downloads/reports/reports/ntds_full.pdf.

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REFERENCES

- Haas, A. P., Rodgers, P.L., Herman, Judy, L. (2014). Suicide attempts among transgender and gender nonconforming adults: Findings of the national transgender discrimination survey. The Williams Institute. Retrieved from <https://williamsinstitute.law.ucla.edu/wp-content/uploads/AFSP-Williams-Suicide-Report-Final.pdf>
- Hassanein, R. (2018, September 12). New study reveals shocking rates of attempted suicide among trans-adolescents. *Human Rights Campaign*. Retrieved from <https://www.hrc.org/blog/new-study-reveals-shocking-rates-of-attempted-suicide-among-trans-adolescents>
- Imberck, K. (2015, April). Transgender Health Primer: Family Medicine Refresher Course. *Uwax University*. Retrieved from <https://u.wiscn.edu/cgi/viewcontent.cgi?article=1053&context=fnrc>
- Kaigle, A., Sawan-Garcia, R., & Fieck, A. (2017). Approach to the provision of transgender health care and a veteran population. *The Transgender Population*.

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REFERENCES

- MAP (2018, May 29). Retrieved from http://www.lgbtmap.org/equality-maps/non_discrimination_laws
- Meagher, T. & Filzmaier, K. (2017). The Medical Underwriting of Transgender Individuals. *Journal of Insurance Medicine*, 47(1), 43-49. <http://dx.doi.org/10.117849/inam-47-01-43-49-01>
- Nichols, J.M. (2016). A survivor of gay conversion therapy shares his chilling story: "We were no longer people at the end of the program." *Glowr Index*. Retrieved from
- Shepherd, J.C., Darling, J.E., Klao, R.S., Rose, D., & Yano, E.M. (2018). Experiences in the veterans health administration and impact on healthcare utilization: Comparisons between LGBT and non-LGBT women veterans. *LGBT Health*, 2(3), 303-311. <http://dx.doi.org/10.1089/LGBT.2017.0179>
- Shuster, S. M. (2019). Performing informed consent in transgender medicine. *Social Science Medicine*, 226, 190-197. <http://dx.doi.org/10.1016/j.socscimed.2019.02.053>
- Turner, A. (2018). HRC releases annual state equality index ratings. State Equality Index 2017. *Human Rights Campaign [Blog]*. Retrieved from <https://www.hrc.org/blog/hrc-releases-2017-state-equality-index>

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REFERENCES

- Valentine, S.E., & Shepherd, J.C. (2018). A systematic review of social stress and mental health among transgender and gender nonconforming people in the United States. *Clinical Psychology Review*, 50(272-7358/17), 30420-30428. <http://dx.doi.org/10.1016/j.cpr.2018.03.03>
- Vermeir, E., Jackson, L.A., Marshall, E.G. (2018). Barriers to primary and emergency health care for trans-adults. *Culture, Health and Sexuality*, 20(2), 232-246. <http://dx.doi.org/10.1080/1369108.2017.1338757>
- Zevin, B. (2017). Homeless transgender individual. *Center for Excellence for Transgender Health, USC*. Retrieved from <http://transhealth.ucsf.edu/trans/?page=guidelines-homeless>
- Zarada, A. Salandy, S. Roberts, W. Gielecki, J. Shrober, J & Loukas, M. (2018). The evolution of transgender surgery. *Clinical Anatomy*, 31(6), 878-886. <http://dx.doi.org/10.1002/ca.23206>

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POST QUESTIONS

- Do you now believe that it is alright to refer to someone who identifies as transgender as *Transgendered*?
- Do you believe that people who have gender dysphoria have a higher than average suicide rate?
- Do you believe that more specialized education is warranted for best health and psychological outcomes for people who identify as transgender?
- Is gender dysphoria a choice?
- Is gender dysphoria minimized with gender reassignment surgery?

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