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Adult Development and Quality of Life of Transgender and Gender Nonconforming People

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Abstract

Purpose of review—Research on the health of transgender and gender nonconforming people has been limited with most of the work focusing on transition-related care and HIV. This review summarizes research to date on the overall development and quality of life of transgender and gender nonconforming adults, and makes recommendations for future research.

Recent findings—Pervasive stigma and discrimination attached to gender nonconformity affect the health of transgender people across the lifespan, particularly when it comes to mental health and wellbeing. Despite the related challenges, transgender and gender nonconforming people may develop resilience over time. Social support and affirmation of gender identity play herein a critical role. While there is a growing awareness of diversity in gender identity and expression among this population, a comprehensive understanding of biopsychosocial development beyond the gender binary and beyond transition is lacking.

Summary—Greater visibility of transgender people in society has revealed the need to understand and promote their health and quality of life broadly, including but not limited to gender dysphoria and HIV. This means addressing their needs in context of their families and communities, sexual and reproductive health, and successful aging. Research is needed to better understand what factors are associated with resilience and how it can be effectively promoted.

Keywords

Transgender; gender identity; lifespan development; quality of life

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Introduction

Public awareness about transgender and gender nonconforming (TGNC) people has recently reached unprecedented heights. The field of transgender health is experiencing a corresponding surge in interest from health providers and policy makers. However, research to inform practice, education, and policy is lagging behind. Examples of TGNC people have been documented across cultures and throughout history. Crossdressing and TGNC identities were first medicalized in the early 20th century, but transgender health did not emerge as a field until the publication of Harry Benjamin's book *The Transsexual Phenomenon* (1). That same year, Johns Hopkins University started providing gender-affirming care followed by the University of Minnesota and other medical centers across the United States (2). Research evaluated how well transgender people functioned as members of the other sex after hormone therapy and surgery (3, 4). Unfortunately, 15 years later, most of these university-based clinics had closed, except for the University of Minnesota and the University of Texas Medical Branch.

In the 1980s and 90s, clinical services were primarily provided in private practice and little transgender health research was being conducted in the United States. Coming from a marginalized position, even within the Lesbian, Gay, Bisexual, and Transgender (LGBT) community, TGNC people came together, empowered themselves, and began to redefine their identity and experience both within and outside of the gender binary (5–7). This renewed visibility led to a stronger coalition between the transgender and the LGB communities. A surge in research followed, particularly as public health reports revealed that TGNC people are disproportionately affected by HIV (8–12). LGBT community health centers began to serve transgender people in larger numbers and facilitated community-based research. Findings indicated that TGNC people's HIV risk had to be understood in light of their overall health affected by social stigma and lack of access to care (13).

In 2011, the NIH commissioned a report from the Institute of Medicine to review the status of LGBT health research, identify gaps and opportunities, and make corresponding recommendations. The review showed that there were more gaps than research, and the IOM recommended NIH implement a broad research agenda in LGBT health and prioritize creation of an evidence-base for transgender care (14). To assist NIH in developing such a research agenda, *TransNet*, a newly formed U.S. network of transgender health researchers, organized a workshop in May of 2015. This report is from the workshop's group charged to review research on adult development and quality of life and make recommendations for future research.

Transgender Identity and Gender Dysphoria

TGNC people are a diverse group of individuals whose gender identity differs from their sex assigned at birth (14). Gender dysphoria refers to distress that some TGNC individuals may experience at some point in their lives as a result of incongruence between their gender identity and birth sex, which may include discomfort with gender role and primary and secondary sex characteristics. *Gender dysphoria* is a diagnosis in the Diagnostic Statistical

Manual of Mental Disorders, 5th Edition (15). However, *transgender* is an identity, not a disorder, and the diagnosis is only applicable when TGNC people experience distress or impaired social / occupational functioning as a result of the incongruence.

Gender dysphoria improves with gender-affirming treatment. Satisfaction with treatment is high (> 80%, regrets < 2%) (16). However, outcome research has primarily followed a binary model of gender, evaluating treatment with hormones, social transition, and surgery, in that order. Gender identity and expression, and gender-affirming interventions have become increasingly diverse. This diversity and the corresponding outcomes have not been systematically evaluated.

Identity Development

Theories of transgender identity development include typologies and stage models. Typologies differentiate TGNC individuals based on age of onset of gender dysphoria (17), degree of crossgender identification (18, 19) or gender role nonconformity (20, 21), and sexual orientation (22, 23). Stage models describe a series of developmental tasks (24–28). For example, Bockting & Coleman (24) distinguish among five stages, acknowledging how stigma attached to gender nonconformity shapes psychosocial identity development (Table 1). Stage models are informed by qualitative research and clinical experience, yet have not been tested empirically. Project AFFIRM, a longitudinal study of transgender identity development across the lifespan (R01HD79603), includes an examination of developmental tasks and stages.

Most research on identity development has focused on the period of social and medical transition. Multiple challenges have been documented in qualitative research, with stigma as an overarching theme affecting mental health (e.g., contributing to increased risk for suicide) (29). Clinical research has focused on the role of transition in alleviating gender dysphoria. However, with a few exceptions (30, 31), what has not been studied is how different ways of transitioning affect health, wellbeing, and quality of life. Generational differences in the approach to transition have been observed clinically, but little research to date has examined such differences.

Social Stigma, Minority Stress, and Resilience

According to the minority stress model (32–34), stigma and prejudice result in added stress beyond general stress also faced by nontransgender people, causing an increase in mental and physical disorders (e.g., depression, anxiety, substance use, hypertension, asthma). Meyer (32) described both distal and proximal minority stress processes. Distal processes are experiences of rejection and discrimination (enacted stigma); proximal processes refer to stress as a result of the internalization of prejudice and stigma. For TGNC people, distal processes include non-affirmation of gender identity (35,36). Proximal processes include internalized transphobia, perceived rejection and expectations of being rejected or discriminated against (felt stigma), and hiding stigmatized status (concealment). Against these stressors, gender minorities forge resilience, coping, social support, and use of other resources (37). The minority stress model describes the impact on health as the net outcome of these negative (stress) and positive (resilience and coping) processes.

TGNC people report verbal harassment, physical abuse, and sexual assault; employment and housing discrimination; and difficulties accessing health and support services (38, 39, 29). A test of the minority stress model with a national sample of the U.S. transgender population showed that discrimination was associated with psychological distress (Bockting et al., 2013). Family support and identity pride were associated with less distress, and support from other transgender people buffered the negative impact of discrimination on mental health. Similarly, in a study of transgender women in NYC, gender-related abuse predicted depression (40, 41), mitigated by community connectedness (35).

Qualitative research has generated other factors of resilience yet to be tested quantitatively, including identity affirmation, awareness of oppression, hope and future outlook, social activism and being a positive role model for others (42). These findings provide support for the minority stress model, yet the mechanisms involved have not been adequately studied. Understanding of such mechanisms is necessary to inform interventions. Project AFFIRM (R01HD79603) is currently testing the development of resilience over time (Fig. 1).

Gender Affirmation

Gender affirmation refers to an interpersonal, interactive process whereby a person receives social recognition and support for gender identity and expression (24, 43, 35). Sevelius (44) proposed a *Model of Gender Affirmation* to provide a framework for research and interventions focused on sexual risk-taking and self-care among transgender women (Fig. 2). A high need for gender affirmation coupled with low access to gender-affirming procedures results in an unmet need for affirmation, which constitutes identity threat. TGNC people may attempt to reduce identity threat by seeking affirmation in contexts that pose risks and undervalue health-seeking behaviors. Interventions that emphasize self-care motivated by empowerment, gender pride, and understanding gender-based power inequalities, may be successful in building sexual negotiation skills and healthy behaviors supported by a sense of self-worth. An unmet need for gender affirmation predicted risk behavior among HIV negative transgender women and treatment failure among HIV positive women (45). Access to gender affirmation, both social and medical, is related to better mental health (46–48). Gender affirmation within and outside of the gender binary is a promising area for future research.

Quality of Life

Quality of life includes mental health, wellbeing, physical function, social function, satisfaction, and happiness. Data from probability samples is lacking in virtually all of these domains. Data from community samples indicate high rates of depression (44%) (38), suicidal ideation and attempts (54% and 31%, respectively) (11). Rates of excessive drinking were comparable to those among LGB people (22%), while rates of marijuana (24%) and other drugs (12%) were high (49). Transgender men reported lower quality of life than both female and male norms (Newfield et al., 2006). However, a review of quality of life after hormone therapy and transition indicated that the majority (80%) showed improvement, including more stable relationships, better psychosocial adjustment, overall

happiness and contentment (50, 51). Perceived financial, professional, and employment status also improved.

Intersectionality

Identity development and quality of life may be affected by sex, type of TGNC identity, sexual orientation, race/ethnicity, geographical location (52), and socioeconomic status (53). Study samples vary in representation of these characteristics. Transgender women are more often the focus than transgender men; few studies have focused on genderqueer / nonbinary identities (54). In public health research, inner-city transgender women of color are overrepresented because they carry a higher burden in HIV and its social determinants. In clinical samples, transgender women of color are underrepresented, reflecting unequal access to care. There are important differences based on these characteristics that need to be better understood to tailor interventions. For example, rural transgender men reported higher levels of depression and lower levels of self esteem than their urban counterparts (52), and genderqueer individuals reported higher levels of stigma than other TGNC individuals; their rates of depression and anxiety were higher (53% and 39%, respectively) (55–57).

Sexual and Reproductive Health

Sexual orientation

TGNC individuals may be attracted to men, women, and/or other TGNC people. Sexual orientation may affect transgender identity development and vice versa (58). For example, transgender men attracted to women may identify as lesbian before coming out as transgender, while other transgender men or women may not explore their attractions toward men until after transition (59, 24, 60, 61). Vulnerabilities and sexual health needs may differ by sexual orientation (62, 63).

HIV

Research has shown disproportionate prevalence of HIV, AIDS-related mortality, and uncontrolled viral load among transgender women (64, 11). Transgender men who have sex with men reported high rates of sexual risk behavior (62, 63, 65). Few tailored interventions have been tested (66, 67, 68, 8, 13, 69, 70, 71, 72), yet several trials are underway (R01HD057595; R01MH094323; UR6PS000422; R01MH106373, R34MH102109, R34DA038541). There are no transgender-specific guidelines for PrEP, despite evidence suggesting unique barriers to uptake and adherence (45, 73).

HIV-positive transgender women are less likely to receive Anti-Retroviral Treatment (ART) and showed worse adherence than other groups (74, 75). They face complex psychosocial challenges that complicate their access to HIV care, including past negative experiences, giving priority to transition-related care, and concerns about ART and hormone interactions (76, 77). Interventions need to address lack of adherence self-efficacy. Integration of hormonal and HIV care may facilitate adherence and decrease self-administered hormone use (78, 79).

Sexual functioning and satisfaction

Few studies have assessed sexual functioning. In an intervention study (69), TGNC participants reported difficulty getting aroused (38%), low sexual desire (34%), difficulty reaching orgasm alone or with a partner (35% and 28%, respectively); some transgender women attributed their sexual functioning problems to hormone therapy (13%). A review of research on sexual functioning after hormones and surgery, mostly conducted in Europe, found rates of low sexual desire among transgender women comparable to those of nontransgender women, while sexual desire of transgender men increased with hormone therapy and surgery (80).

Reproductive health

In a recent study of transgender men who had delivered a child, 80% used their own eggs, 61% had used testosterone previously, and some pregnancies were unplanned (81). Questions remain about long-term fertility and best practices to preserve (before hormone therapy) or regain (after hormone therapy) fertility in both transgender men and women, and to retain ovaries after hysterectomy for possible future harvesting in transgender men. Questions also remain about the impact of prior testosterone use on a current pregnancy, how long before pregnancy testosterone should be discontinued, and how to counsel a pregnant patient who still has circulating testosterone levels.

Sex work

Sex work is common, particularly among transgender women, attributed to economic hardship, employment discrimination, and lack of health insurance coverage for transgender-specific care (82). HIV prevalence is more than five times as high among transgender compared to nontransgender female sex workers, and substantially higher than among transgender women not engaged in sex work (83). Qualitative research suggests that transgender women may be introduced to sex work by finding community on the street and, initially, as part of their quest to affirm gender identity (66). Research is needed to understand sex work in context of identity development and to test interventions aimed to reduce harm and improve sex work conditions (84).

Relationships, Family, and Community

Few studies have focused on TGNC people’s relationships and family. Of 10,739 articles in scholarly family therapy journals, only 9 focused on transgender issues (0.0008%) (85). Studies are mostly qualitative and samples are small. Some studies conceptualize how parents or spouses deal with a loved one’s transition, depicting loss, grief and cognitive restructuring (86, 87, 88). While family support is a protective factor in coping with minority stress and associated with better quality of life (38, 89, 90), family rejection is as high as 57% and 19% reported family violence (39). Among transgender women of color, family rejection in childhood had lifelong negative sequelae (91).

Research on families with a transgender parent is scarce. An early study by Green (92) showed that children of transgender parents did not differ from children raised in more traditional settings. A few studies examined changes in the parent-child relationship after

transition (93, 94, 39, 95, 96); younger age at transition and a positive relationship between parents proved protective (94).

TGNC people's work life is also largely unexamined. Social stigma may disrupt or delay education and career development, and transgender people worry about the impact of transition on the job. In a U.S. national survey, 38% of transgender adults reported problems getting a job and 23% reported losing a job because of being transgender (38). TGNC people are more likely to be unemployed (33% vs. 12%) and live under the poverty level (31% vs. 9%) (53). Research is needed to better understand the challenges encountered in the workplace and how these can be prevented or overcome.

Incarceration is a public health concern disproportionately affecting transgender women. Among a U.S. sample of 3,878 transgender women, 19% reported incarceration (96). Transgender women of color were 1.8 to 3.3 times more likely to report incarceration than White women. The housing of TGNC people in custody in sex-segregated facilities and their access to care remain contentious. Interventions are needed for transgender women affected by the syndemic of incarceration, HIV, mental illness, and substance use (e.g., R34DA038541).

Brain Development

Research on the brain of TGNC individuals can clarify etiology of gender dysphoria and provide clinically relevant information about the effects of puberty suppression and gender-affirming hormone therapy on the brain. *Post mortem* studies conducted in the Netherlands (97–100) have linked gender dysphoria to sex differences in the brain. MRI studies using voxel based morphometry, cortical thickness, and diffusion tensor imaging indicate that the transgender man's brain phenotype consists of a mixture of feminine, masculine and defeminized characteristics, whereas the transgender woman's phenotype consists of feminine, masculine and demasculinized characteristics (101–108). fMRI studies have focused on sexually dimorphic characteristics, such as mental rotation (109–111), handedness (112), and response to erotic stimuli (113–115). PET studies have addressed hypothalamic responses to putative pheromones acting in a sexually dimorphic manner (Berglund et al, 2008). These studies point toward the existence of distinct phenotypes of the brain for both transgender women and men. More integrative work is necessary to illuminate etiology and understand the effects of hormone therapy on the brain and related health and quality of life indicators.

Opportunities include testing the hypothesis that TGNC people may experience a form of intersexuality of the brain. For example, studies could correlate AR, ER, CYP19, CYP17 and other gene polymorphisms and structural brain data. Another potential area of research concerns the role of body perception and image in the development of gender dysphoria (116–119). MRI cortical structural findings in both transgender women and men have shown initial support for such a role (120, 121). The neural network of body representation appears to differ between transgender and nontransgender individuals (122). For research on etiology, it should be recognized that TGNC people are not a homogeneous group. MRI

studies must compare the expression of sex differences in TGNC people of varying sexual orientation and age of onset of gender dysphoria.

While serious short-term complications of gender-affirming hormone therapy appear uncommon (123), the longer-term effects on vulnerability to cardiovascular disease, metabolic disease, and cancer are not well understood (124). Studies that examined the effects of hormones on the brain (125, 126, 121) showed dramatic changes in intracranial volume, cortical thickness, volume of sub-cortical structures, and fractional anisotropy. Transgender women experienced a decrease of gray matter that produces an expansion of the ventricles, while transgender men experienced an increase of intracranial volume, cortical thickness and FA values. These results were interpreted as deep changes in brain metabolism in relation to androgen suppression in transgender women and exogenous testosterone in transgender men (121).

Among nontrangender women, menopausal estrogen therapy has been associated with smaller regional volumes in frontal, temporal and limbic regions as well as the hippocampus (127, 128). Among women aged 65 and older, estrogen therapy was associated with greater brain atrophy (128). In addition, female sex steroids increase the risk of meningioma (129). These data are relevant for aging among TGNC people; the metabolic mechanism that produces changes in the brain of those receiving lifelong hormone therapy needs to be better understood.

Aging and End-of-Life

Transgender people aged 50 and older are at higher risk for poor physical health, disability, depression, and perceived stress (130) compared to their LGB counterparts. These differences are in part due to fear of accessing health services, lack of physical activity, internalized stigma, victimization, and lack of social support. Barriers to care are amplified by the lack of available culturally competent services. In addition, ageism, lack of affordable housing, and lack of family support appear to besiege TGNC older adults (131–136).

It is not uncommon for TGNC individuals to present for transition-related care in mid or later life when social, identity, and biological forces appear to converge and affect the clinical presentation (137). Changes in cortisol secretion and the down regulation of sex steroids and other hormones possibly intensify gender dysphoria (138). The impact of these factors on quality of life of transgender older adults has not been adequately studied.

A review of research on end-of-life care yielded no studies related to TGNC people in hospice or similar situations (139). This despite reports that transgender people fear that their gender identity will not be respected in long-term care and hospice facilities (140). One case report outlined some of the challenges transgender elders and their providers might face (141).

Recommendations for Future Research

Based on the above review and discussions at the May, 2015 NIH workshop on transgender health research, we recommend the following priority areas for future research on adult development and quality of life:

1. Intervention research to reduce stigma and promote resilience

Population studies with probability samples are needed to more accurately determine the prevalence and predictors of health concerns among TGNC people. This will inform research to understand the mechanism of how stigma and minority stress affect health; what constitutes resilience and how it develops over time; and what interventions (individual, family, community, and societal) can effectively promote health across the lifespan.

2. Impact of transition, medical and social, on quality of life

In addition to research on benefits and risks of medical interventions, the impact of transition on quality of life needs to be better understood. This includes mental health and wellbeing, education and employment, housing, social function, satisfaction and happiness.

3. Diversity in gender identity and expression (particularly for nonbinary identities), and ethnic/racial intersectionality

The full spectrum of diversity within this heterogeneous population needs to be further described and accounted for. This includes identifying heightened vulnerability for health concerns among subgroups based on type of transgender identity or race/ethnicity.

4. The role of family, social, and community support (incl. faith community) in quality of life

While social support has repeatedly been shown to serve as a protective factor, the various sources of support need to be better understood to inform interventions. This includes understanding the needs of families and communities.

5. Sexual and reproductive health, dating, relationships, sexual functioning and satisfaction, assisted reproductive technologies, and HIV

Sexual orientation and the impact of stigma on dating and relationships of TCNC people are understudied. Research is needed on sexual functioning and satisfaction, and how it is affected by transition-related care. While an increasing number of TGNC people access reproductive technologies, evidence to guide treatment lags behind. HIV remains a significant concern and research is needed to address transgender-specific risks and barriers to prevention and care. Evidence is lacking to inform appropriate screening for other sexual health concerns (e.g., pelvic and prostate exams).

6. The impact of medical interventions on brain development

Methodological advances are improving our understanding of brain development, providing new opportunities to understand how transgender-specific care affects the brain and related

health and quality of life indicators. Moreover, neuroscience can contribute to understanding sexual differentiation of the brain and its implications for health and human development.

7. Successful aging, including end-of-life care

A life course perspective should examine TGNC people's quality of life across the lifespan while accounting for diversity in gender identity and expression (i.e., including nonbinary identities). We recommend a biospsychosocial approach, examining the impact of life course events, experiences, and interventions (e.g., hormone therapy) on the dimensions of successful aging (physical and mental health, social engagement and wellbeing).

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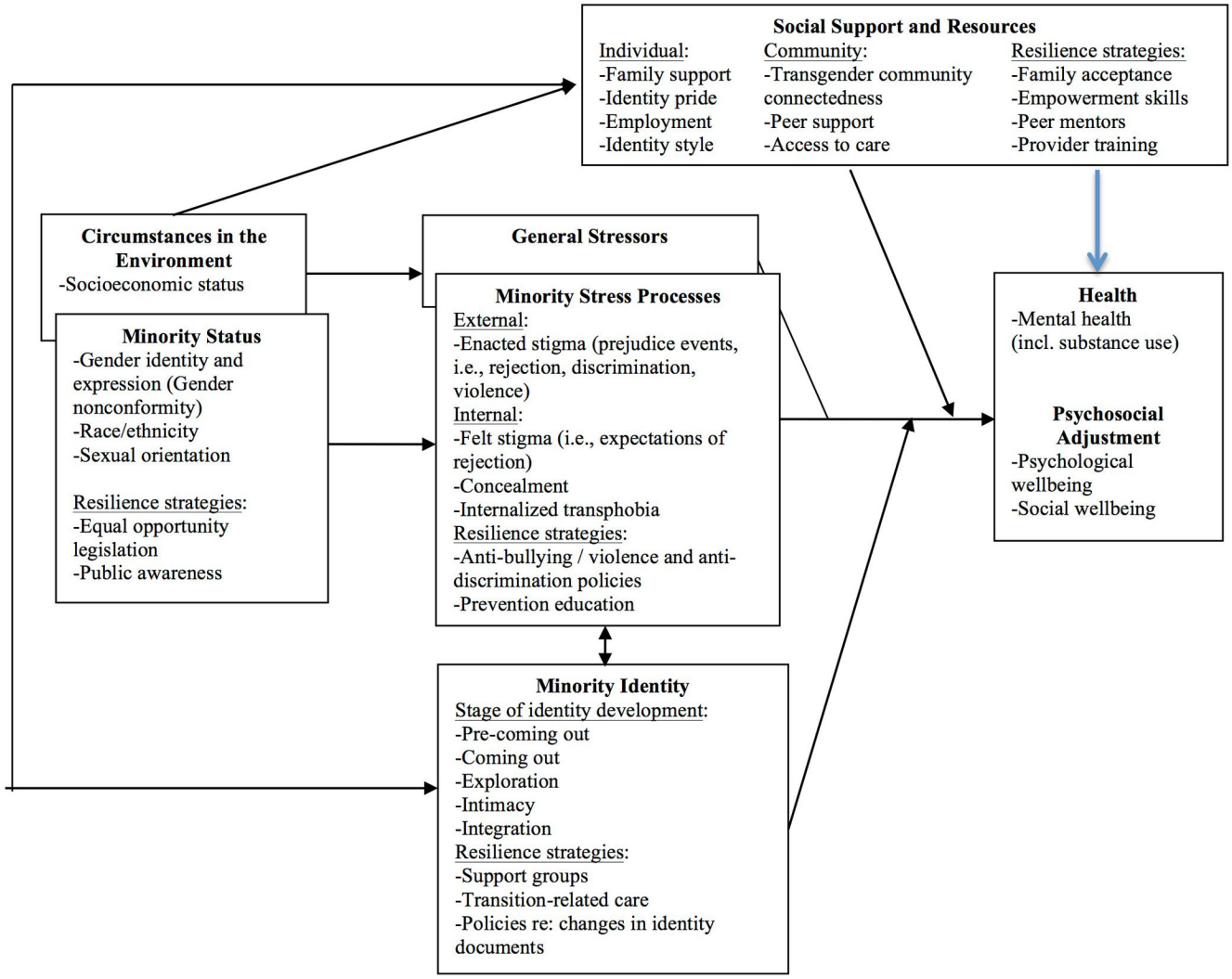

Figure 1.
Adaptation of the minority stress model to transgender health

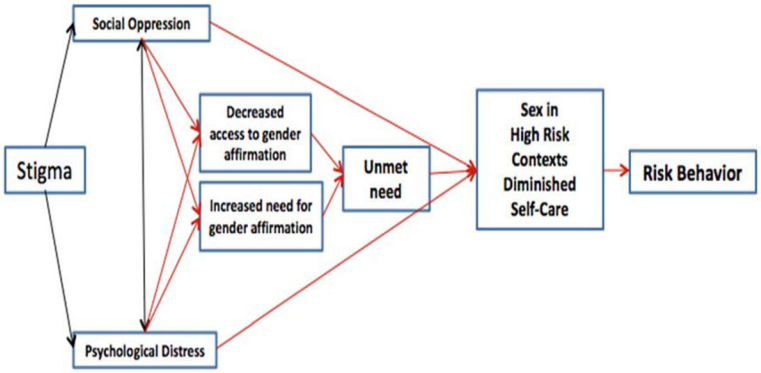

Figure 2.

Model of Gender Affirmation.

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Table 1

Developmental Stages of Transgender Identity Development

Stage	Challenges/tasks
Pre-coming out	Feeling different; stigma; early resilience or concealment
Coming out	Acknowledgment to self and others; taking calculated risks
Exploration	Experimentation; stereotyped notions of femininity and masculinity; personal attractiveness and sexual competence; transforming shame into pride
Intimacy	Desire for intimacy and first relationships in preferred gender role; facing fear of abandonment; sexual orientation identity
Identity integration	Grief; less preoccupation with identity labels; tolerance of gender ambiguity