

Competent Care of the Transgendered Patient: Nurses as Advocates

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I have no problem passing in real life, but once I step into a situation like psychology or medicine where I'll probably be stripped bare, the stress level jumps up. I have to breathe slowly and count backwards and think of flowering meadows populated by bounding puppies just to have my blood pressure taken (J., personal communication, February 3, 2004).

Introduction

About 1 in 11,900 males and 1 in 30,400 females are transsexual. Typically from early childhood these individuals sense that they are the opposite gender from their biologic and genetic sex (HBIGDA, 2001). In contrast to having a strong *urge* to be the opposite sex, these individuals feel they already *are* the opposite sex but have been born with the wrong body. Both the DSM-IV and the ICD-10 currently classify a range of diagnoses relating to gender identity disorders (GID), including the diagnosis of transsexualism, defined as “the desire to live and be accepted as a member of the opposite sex, usually accompanied by the wish to make his or her body as congruent as possible with the preferred sex through surgery and hormone treatment” (HBIGDA, 2001). Individuals at the transsexual end of the spectrum probably total less than 30,000 in the United States.

Transgendered¹ individuals face a unique set of challenges in the health care setting. As with any rare condition, patients are disproportionately burdened by the sheer rarity of their situation. Stress levels are compounded by the lack of knowledge among physicians, lack of research and clinical trials, and the sense of overwhelming isolation associated with having a

¹ The term “transgender” is used informally to describe any person with any type of gender identity issue without ascribing a formal diagnosis. It will be used here to refer in a general manner to patients with atypical gender identities, regardless of surgical intentions or status.

condition that no one else you know has ever had (Krammer, 2003). For the transgendered patient, these issues are only the beginning. They are also at risk for insensitive and uninformed care due to the lack of professional awareness concerning the realities and needs of the transgendered population (Berreth, 2003). Unlike most other conditions, transsexualism inspires a morbid curiosity that unfortunately often extends to members of the health care team.

Nurses are in an ideal position to improve the quality of care these patients receive. Whether a hospitalization is related to sex reassignment surgery or a broken bone, a professional level of knowledge combined with sensitive and empathetic care can help reduce needless stress and facilitate the healing process. While it is neither necessary nor likely that more than a handful of hospitals will specialize in the genital surgeries for gender identity disorders, all health care facilities should be adequately prepared to provide competent and compassionate care for patients with GID. By becoming familiar with recent research and striving to understand the lived experience of the transgendered patient, nurses can become vital advocates for these individuals for whom health care will always entail a unique anxiety.

Review of Literature

Nursing care of the transgendered patient has received little attention in the literature, where research has focused primarily on the psychopathology of transgenderism. Berreth (2003) recognized the importance of considering the needs of transgendered clients as a subset of the geriatric population. Frequently estranged from family members, older transgendered adults are at high risk for depression and substance abuse. Berreth also highlights the need for recognition of some characteristic health risks associated with hormone therapy, surgeries, and the continued need to screen for diseases of the biologic gender (e.g., prostate cancer in male-to-female transsexuals).

Some attempts have been made to provide a general edification for the nursing profession in order to improve the quality of care afforded transgendered patients. Colucciello (1996) sought

to identify and correct misconceptions among nurses that could compromise care. By outlining the rigorous diagnostic criteria that must be met for patients to even be considered for hormonal and surgical treatment, the author underscores the need for recognizing and empathizing with the profound emotional impact of gender identity disorders. Other authors have highlighted the tendency for the patient's transgendered status to overshadow other significant medical needs (Beemer, 1996; Kirksey, 1995; McKeown & McCusker, 1995).

Beemer (1996) examined interactions between nurses and their transgendered patients. The author asserts that curiosity that "borders on the voyeuristic" may cause nurses to overstep their clinical boundaries by asking personal questions that are irrelevant to patient care. Not only is this detrimental to the therapeutic relationship, but it also strains the emotional resources of the patient at a time when they can ill afford it. Most transgendered patients have no desire to act as educational resources for the medical profession, and the author suggests caregivers educate themselves via other channels. A key source of stress is the use of names and pronouns. Beemer asserts that caregivers have the responsibility to seek out and acknowledge the preference of their clients, regardless of what medical or legal records may state. This is a fundamental theme noted by a number of other authors (Berreth, 2003; Colucciello, 1996; Kirksey, 1995; Rees, 1993).

Society's assumptions regarding the etiology of transsexualism influence both the direction of research and treatment of transgendered individuals. Existing psychological, medical, and nursing standards of care have been predicated on the prevailing psychological paradigm that classifies gender identity disorders as a mental illness—albeit an incurable one for which surgery may be a lifesaving intervention (Kirksey, 1995). Recent research findings are challenging these assumptions. Studies conducted by Kruijver et al. (2000) strongly support a neurobiological basis for gender identity disorders. A specific region of the hypothalamus, the bed nucleus of the stria terminalis (BST), contains nearly twice as many neurons in males versus females. Kruijver found that the numbers of BST neurons in male-to-female transsexuals conclusively corresponded with female brain structure rather than male in each of 42 specimens.

These findings provide compelling evidence that transsexualism may result from altered development of sexually differentiated regions of the brain. One hypothesis is that abnormal exposure to sex hormones during fetal development causes the brain to sexually differentiate in a manner opposite the genitals. The proliferation of endocrine disrupting chemicals (e.g., PCBs, DDT, and other pesticides) has been advanced as one source of these developmental effects, as endocrine disruptors have been shown to cause a number of other reproductive effects. A reclassification of gender dysphoria as a congenital neurological defect would have profound effects on research, treatment, and social perceptions affecting these individuals.

The Lived Experience of GID

Gender identity disorders manifest in as many ways as there are individuals. International standards of care have been developed for use as clinical guidelines, however not all patients will need or want particular aspects of treatment. The goal of therapy, whatever form it takes, is “lasting personal comfort with the gendered self in order to maximize overall psychological well-being and self-fulfillment” (HBIQDA, 2001). For some individuals, progressing to genital surgery is indicated, while for others, taking on the felt gender role with the aid of hormone treatments produces acceptable results. It is important for health professionals to recognize that, for a variety of reasons, many transgendered individuals have no plans to alter their genitals surgically. Nevertheless, they live permanently and successfully in their felt gender role, blending unobtrusively into the community (Rees, 1993).

The clinical pathway to gender reassignment is a long and arduous one. Clients seeking to enter hormonal or surgical therapies must meet strict eligibility requirements. Patients generally must be 18 years old before being considered for hormone therapy. Typically a brief (usually three months) real-life experience in the felt gender must be documented before hormones are prescribed. Readiness to proceed is certified in a letter of recommendation from a qualified mental health specialist. Longer real-life experiences (typically one year) are required

before seeking eligibility for surgery. Two qualified specialists must concur with the recommendation for surgical treatment (HBIGDA, 2001).

Hormones

Hormonal therapy for the male-to-female (MTF) patient consists of a regimen of anti-androgens combined with estrogen. The goal is to reduce testosterone to that of normal female levels, while inducing feminization with an estrogen or estrogen combination. Spironolactone is a drug of choice for anti-androgenic activity because of its relative safety and low cost. Adverse effects are rare but contraindications include renal insufficiency, elevated serum potassium levels, or concurrent use of digoxin, ACE inhibitors, and other potassium sparing diuretics. For estrogen therapy, conjugated estrogen (Premarin) is a typical starting drug. Aspirin is also typically prescribed to reduce the risk of thromboembolism. Risks of estrogen therapy are well known, and patients need to be fully informed of the potential for adverse effects. Estrogens interact with dozens of other drugs so it is also important to monitor medications closely. Responses to estrogens are highly variable, and because patients may believe that “more is better,” education is a key part of therapy (TWHC, 2001).

Testosterone is the mainstay of hormonal treatment for female-to-male (FTM) patients and many make successful transitions to the male role on hormone therapy alone. The complete process of virilization may span several years, but administration of intramuscular or transdermal testosterone usually produces satisfactory changes in voice pitch, muscle mass, and hair growth within a few months. Oral preparations are typically not used because of extensive liver metabolism and increased risk of liver disease. Patients who are obese, who smoke, or have a history of liver disease, coronary artery disease, or hyperlipidemia are at increased risk. Testosterone increases the effects of warfarin (Coumadin) and lowers blood sugar, thus requiring changes to diabetic regimens (TWHC, 2001).

Surgery

Surgical treatment is medically indicated and medically necessary in cases of transsexualism or profound gender identity disorder (HBIQDA, 2001). Studies have continually reaffirmed that sex reassignment surgery is valuable for those patients for whom it is indicated (Beemer, 1996). Mastectomy in FTMs and breast augmentation surgery in MTFs are typical. Other procedures for improving gender presentation include vocal cord surgeries, tracheal “shaving,” rhinoplasty, liposuction, and electrolysis. Genital surgeries are available for both MTF and FTM patients. Cosmetic and functional results vary and there is a high risk of complications. Any genital surgery involves a lengthy and painful recovery period with long term implications such as daily dilatation for the MTF. For these and a variety of other reasons, the majority of transgendered individuals have not had genital surgeries and may not plan to (TWHC, 2001). Cost of surgery is often a prohibitive factor, as most insurance companies still do not cover it. Since living comfortably in a gender role does not depend on genital surgery, many believe the costs outweigh the benefits (Rees, 1993).

Psychosocial Experience

Most people diagnosed with transsexualism sensed from early childhood that they had the wrong body. Treatments that are not fully reversible are delayed as long as possible and conservatively introduced in adolescent patients. Thus it is almost inevitable that transgendered adults will have significant social and developmental deficits as a result of growing up “in limbo.” The lack of normal childhood interactions with peers, often characterized by unkind or even violent encounters, systematically crushes self-esteem and limits the development of interpersonal skills (Anderson, 1998). Not surprisingly a high percentage of these individuals develop depression and/or anxiety disorders secondary to their gender dysphoria. High rates of substance abuse and sexually transmitted infections have also been noted (TWHC, 2001). As many as 60% may attempt suicide (Rees, 1993; Kirksey, 1995). Clearly the lifelong psychosocial burden associated with this condition is staggering.

Few can imagine the depth of frustration, anger, and isolation experienced by transsexuals. Watching others form relationships, marry, and become parents is a source of immense grief and frustration (Rees, 1993). Years of torment and misunderstanding by peers and family members causes anger to build up (McKeown & McCuster, 1995; Rees, 1993). Anger turned inward results in depression and even suicide; anger directed outward exacerbates social isolation and contributes further to depression. The loneliness imposed by GID is often compounded by a lack of support and even open hostility from family members, who may insist that individuals with GID bring these problems on themselves (Anderson, 1998; Rees, 1993). Normal mechanisms of personal strength and support, e.g., from parents and siblings, may be nonexistent in these individuals' lives (Berreth, 2003).

Reluctance to seek health care is common. Transgendered men and women are understandably anxious about having their status "outed" unnecessarily. Paranoia stemming from prior experiences with clumsy, uninformed, or rude physicians keeps many transgendered patients from seeking appropriate care. (Berreth, 2003; TWHC, 2001). The account by Kirksey et al. (1995) of the unprofessional treatment of a MTF patient by emergency room staff exemplifies the scenario that transgendered patients can readily imagine if they haven't already experienced it themselves. In this case, upon the discovery that a patient, "Maria," had a penis, she was moved to a trauma room with three men, where she was subjected to jeering and name-calling by the patients and staff. The paradox is that the medical realities of transsexualism require careful clinical monitoring: patients on long term hormone therapy are at increased risk for liver and cardiac disease, cancer, thromboembolisms, or other life threatening problems depending on their hormone regimens and other risk factors (Berreth, 2003).

Transgendered patients report a number of common problems in their encounters with health care professionals. Getting names and pronouns right seems to be one of the biggest hurdles for people to overcome in their interactions with transgendered patients. (Beemer, 1996; Rees, 1993; and others). Staring, along with looks of disgust or fear are also common occurrences

(Beemer, 1996; Coluciello, 1996). Well-meaning nurses may also offend by asking intensely personal questions, perhaps in trying too hard to appear clinically interested. Lack of knowledge regarding the basics of hormonal treatments and the associated effects they can have on lab values was also noted (Beemer, 1996). Finally, nurses' personal discomfort around transgendered patients has no doubt resulted in instances of inadequate, untimely, and inattentive care. As with any patient in their care, nurses need to be able to overcome any sources of personal discomfort to achieve optimal therapeutic outcomes for their patients (Coluciello, 1996).

Implications for Nursing Care

Specific pre- and post-operative nursing interventions related to the various types of MTF and FTM genital surgeries are outside the scope of this paper. However, by addressing a broader range of nursing diagnoses applicable to this population, nurses can foster vast improvements in their health care experiences and alter expectations regarding future care. The overall goal is to relieve prevailing apprehensions regarding health care to promote better health maintenance among a population with higher than average health care needs.

Nurses may have the opportunity to provide care for transgendered clients in a variety of situations and settings:

- follow up surgeries (e.g., cosmetic)
- complications or related long term issues
- unrelated medical or surgical issues
- routine health care
- emergency care (including cases of violence or elder abuse)
- as family members of other patients

A number of functional health patterns may be at risk for the transgendered patient. In particular, alterations in health perception-health management, self-perception-self-concept, role-relationship, and coping-stress tolerance patterns are anticipated. Consideration of the following representative nursing diagnoses and implementation of appropriate interventions will not only enhance the current therapeutic relationship, but also serve to alleviate patients' anxiety regarding future encounters.

I. Ineffective health maintenance related to lack of accessibility to quality care for transgendered clients

Goal: Transgendered status does not hinder the patient from obtaining appropriate health care.

Interventions:

1. Become familiar with basic standards of care, hormonal treatments and associated risks and contraindications, general surgical options, and psychosocial implications of GID.
2. Develop local resources for health care professionals to improve their competence in caring for transgendered clients in a variety of circumstances.
3. Market the availability of knowledgeable and sensitive care to the transgendered community.
4. Evaluate the potential for a health care delivery model similar to the San Francisco Health Department's "Transgender Tuesdays" to encourage regular health care in the transgendered population.
5. Advocate for removal of legal and administrative barriers to health care in GID, i.e., appropriate insurance coverage for health screenings related to biologic gender (prostate screening for MTFs, Pap screening for FTMs).

II. Anxiety related to expectation of insensitive treatment

Goal: Patient experiences less discomfort in the health care setting.

Interventions:

1. Demonstrate respect by referring to the patient by the name and proper pronoun they normally use, regardless of what the "gender of record" may state.

2. Focus on the needs of the patient as opposed to your own discomfort or curiosity.
3. Maintain a professional attitude—refrain from staring, commenting, or other forms of disapproval, and model appropriate behavior for other staff.
4. Avoid dwelling on the gender issue if it is unrelated to the reason for the health care visit.
5. Help put the patient at ease with perfunctory questions and body language that suggests you see patients with similar issues every day.
6. Provide opportunities for patient to voluntarily disclose personal information they think is relevant, e.g., Is there anything else you think we need to know today?
7. Protect patient from unnecessary stress factors by limiting exposure: private room, general medical/surgical units, primary nursing, etc.

III. Support system deficit related to isolation from family and friends

Goal: Patient is provided resources for emotional support.

Interventions:

1. Encourage and facilitate patient contact with existing social or family network.
2. Capitalize on nurse's credibility to educate family members and friends regarding the diagnosis of GID.
3. Where applicable, prepare visitors regarding patient's appearance or demeanor in order to enhance their abilities to provide support.
4. Assist patient in locating additional resources such as local or Internet support groups.
5. Monitor patient's needs and provide additional emotional support as needed, e.g., spend time with the patient.
6. Monitor patient's response to visitors and minimize stressful interactions to facilitate the healing process.
7. Investigate the possibilities for a therapeutic roommate relationship if applicable.

IV. *Ineffective coping related to life stress associated with GID*

Goal: Patient utilizes healthier coping mechanisms and is satisfied with their effectiveness.

Interventions:

1. Assess patients use of substances, high risk behaviors, or other detrimental coping mechanisms.
2. Assist patient in identifying desired level of emotional health and/or use of tobacco, alcohol, or other substances.
3. Ensure understanding of the increased risks of cardiovascular and liver disease associated with hormone therapy when combined with alcohol and tobacco.
4. Maintain nonjudgmental attitude and understand that individuals with GID do not necessarily desire a longer life: respect autonomy and self-determination.
5. Teach additional coping skills that build incrementally on patient's own mechanisms and goals for emotional wellness.
6. Provide referrals to appropriate mental health specialists where applicable.

Conclusion

Most of the above nursing interventions reflect a basic theme: Treat these patients the way nurses are expected to treat patients. Nurses are taught to maintain unconditional positive regard for their patients, to advocate for those who need it, and to provide knowledgeable and skilled care. Patients with GID want to be treated respectfully, competently, and professionally, but perhaps above all, just like anybody else. The fundamental and lifelong stresses associated with being transgendered take their toll: medically, socially, and emotionally. Competent and responsive health care is essential, and nurses can be especially valuable allies in creating it for clients with GID.

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