Transgender Treatment Bulletin

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What is the Role of the Helping Professional?

by Dallas Denny FII F COPY

here is a dilemma inherent in persons who request medical treatments to change their bodies, yet resent the professionals who deliver those treatments. Certainly, some transgendered and transsexual people have such resentments. But it is no less perplexing that those very same medical treatments

have historically been very difficult for transgendered and transsexual people to obtain. One reason for this is because the medical treatments necessary for sex reassignment are contingent upon approval from mental health professionals (Walker, et al., 1985).

The protocols which arose in the 1960s and 1970s to treat transexual people were based on pathology-based models which presumed that persons wishing to alter their bodies had a mental illness called gender dysphoria (now gender identity disorder) which

was resistant to psychotherapy and other "cures," but for which sex reassignment could afford some relief (Fisk, 1973). Sex reassignment had as its goal the transformation of dysfunctional males into functional heterosexual women, and dysfunctional females into functional heterosexual males (Kessler & McKenna, 1978). It was assumed that clients desired to approximate as closely as possible the sexual organs, appearance, and mannerisms of the other sex, even if that meant submitting themselves to intrusive, expensive, and even disfiguring medical procedures. Gender programs expected their clients to blend into mainstream society after treatment, and considered those who would not

or could not to be failures (cf Blanchard & Steiner, 1990). Often, clients were expected to dress and behave as sexual "Barbie and Ken" stereotypes and show "heterosexual" sexual interest; those who did not desire genital surgery and those who were unable to conform to the expectations of these clinics were often turned

away without treatment (Denny, 1992).

Our challenge is to rethink the issue of access to hormonal and surgical treatment, balancing the right of the individual to control his or her own body with the ethical obligation of the caregiver to do no harm. It's a difficult equation with many variables, some of which may never be properly defined.

Such a model seems naive today, but it has only been in the past few years that it has begun to be seriously questioned. Today, many clinicians realize it is possible to live productively as a member of the other gender without genital surgery, and that embarking on a process of body change with hormones does not necessarily mean the goal is surgery or even full-time crossliving. Unfortunately, this realization is not universal. There

are individual caregivers and even some gender programs that still require their clients to conform to their demands about choice of name, hairstyle, mode of dress, occupation, and even sexual orientation (Petersen & Dickey, 1994). A recent (1995) issue of the newsletter of the Harry Benjamin International Gender Dysphoria Association noted that the organization is still undecided about whether it should concern itself only with "transsexuals;" i.e., those who desire genital surgery, or with all persons who desire to masculinize or feminize their bodies. The fact that this is even open to debate is a call for more and better education of caregivers.

Kessler & McKenna (1978) noted that requirements imposed on transsexual clients by mental health and medical professionals were often arbitrary and capricious; for example representative of one gender clinic told them they weren't "taking Puerto Ricans any more; the Puerto Ricans all looked like homosexuals." Bolin's (1988) field study clearly showed that the power dynamics of a relationship in which a therapist serves as a "gate-keeper" for access to medical procedures is out of balance and causes resentment in the client. This imbalance has been a source of frustration to both therapists and to their transgendered and transsexual clients.

Certainly the clinician, confronted with a series of clients who have been struggling for years with gender identity concerns, is likely to see confused, anxious, and somewhat dysfunctional individuals. It is not surprising that clinical impressions of transsexual people and the literature which has arisen from studying them has centered around the transgender phenomenon as pathological. However, it is also possible to view the same clientele as individuals who have been struggling for years with very powerful feelings of gender dysphoria without access to sources of support which would be available for almost any other human condition, but which were unavailable to the clients simply because of the nature of their struggle. Parents, siblings, partners or spouses, children, the extended family, teachers, clergy, and friends often either do not know about the gender issue, or have been told and have exhibited negative or even catastrophic reactions. Being without support in such a situation is very much like being swept down a raging river. In such a circumstance, one is in danger of drowning unless one can grab a tree branch. With that single source of support, it is possible to pull oneself out of the river. Perhaps what is remarkable is that so many transsexual and transgendered persons have coped so well with their condition in the face of adversity.

Clients who go to therapists for support are not particularly likely to do so when everything is going well. This is as true for someone with transgender or transsexual issues as it is for a a single parent with a behaviorally disturbed child. A few weeks of exposure to a support group, a knowledgeable and supportive therapist, or even a friendly electrologist or primary care physician can result in a much calmer and less dysfunctional client. As such support becomes increasingly available, the frantic, confused clients who once presented for intake are being replaced by more knowl-

edgeable, more determined clients. Some, of course, have mental health concerns in addition to gender dysphoria — but most don't.

As a society, we have a dysphoria about gender. Our notions of manhood and womanhood have been rigid and stereotyped, leaving those who varied from the norm out in the cold. Masculine women, feminine men, gay men, lesbians, crossdressers, fetishists, transsexual people, intersexed people, and other gendertransgressive persons have historically received messages that they are sick, deviant, unworthy, and sinful. Unfortunately, our medical and psychological sciences have mirrored this discomfort with difference and concentrated on turning "deviant" people into "normal" ones. The assumptions made when conducting research on transsexualism, the assumptions made by clinicians when confronted with transgendered or transsexual clients, and the assumptions of the clients themselves led to the formation of a pathology-based treatment system which has labored along, after a fashion, for more than 40 years. But those assumptions have changed - and the methods of delivering treatment must change, as well.

I have argued [AEGIS News, 1(5), 1995] that a sea change is occuring in the way we think about gender. I believe it is time to rethink our assumptions about treatment, reinterpret the empirical data, and reexamine the power balance between client and caregiver.

This does not mean that we should throw the baby out with the bathwater. I absolutely do not advocate that medical procedures should be available on demand. Hormones and surgery are powerful technologies, and society has restricted access to them for good reason. Many people who ask for them have unrealistic expectations about what they will and will not do; others may seek them out because of desperation or frustration; and some, because of mental illness, are unable to give informed consent.

Our challenge is to rethink the issue of access to hormonal and surgical treatment, balancing the right of the individual to control his or her own body with the ethical obligation of the caregiver to do no harm. It's a difficult equation with many variables, some of which may never be properly defined. And it's an issue which we will revisit in future issues of this newsletter.

(See Page 8 for References)

Meeting the Reproductive Needs

Of the Transsexual Patient

by Anne Lawrence, M.D.

Dr. Lawrence delivered the following address on June 21, 1997, during the transsexual physicians' panel at the 2nd International Congress on Sex and Gender Issues in King of Prussia, PA. She acknowledged that her presentation had been greatly influenced by conversations with fellow transsexual physician Joy Diane Shaffer, M.D., to whom she dedicated her remarks — Ed.

When I was 25, I had no desire to have children, and it didn't seem likely that I would ever want any. But somehow, by the time I turned 36, things had changed. I wanted very badly to be a parent — ideally, to create a child together with a partner I loved. At that time, I was still living as a man. Consequently, I was able to become the biologic parent of two wonderful children, Kate and David Lawrence. I love them more than anything in the world.

If I had transitioned at 25, that choice would have forever been foreclosed to me, because hormone therapy and castration would have rendered me sterile. Today that is the fate of virtually all transexual women and men who transition without having had children. Oh, certainly I could have adopted, or could have married a partner with children, and I'm sure that would have been satisfying in its own way. But I would never have been able to do what most adults worldwide choose to do at some point in their lives — become the biologic parent of a child. This urge is so powerful that every year infertile couples in Western countries spend millions of dollars trying to become biologic parents. I have cared for dozens of such would-be parents, and I can testify to the intensity of their desires. And I can also testify that this desire is present in many childless transsexual persons, too.

When non-transsexual men and women undergo procedures likely to render them sterile, how are they treated? This issue often comes up during cancer treatment, because chemotherapy and radiation can result in infertility. The standard of care here is not indifference, nor is it silence. Most authorities recognize an obligation to counsel cancer patients about reproductive consequences, and about preserving reproductive options, whenever treatment is likely to induce sterility. Consider this example, from a recent journal article:

Semen cryobanking should be offered by the attending physician as a viable option for any pretherapy male patient who ... considers the future possibility of having children.

- W. Sanger, et al. (1992), Fertility and Sterility 58: 1024

And here's what a recent textbook had to say:

Sperm or ova banking are ... important considerations, and should be discussed with patients about to begin therapies that will likely result in sterility and for whom reproductive concerns are important.

- M. Abeloff (1995), Clinical Oncology, p. 825

That is the standard of care — except for transsexuals. I'd bet that few, if any, of the transsexual men and women present at this conference were counseled about reproductive consequences prior to starting hormone therapy, or were offered the options of banking sperm, ova, or fertilized embryos. And that's a shame. Why aren't we treated as well as cancer patients? I'd hate to think that we aren't considered worthy to have children. I suspect that our caregivers either believe we won't be interested, or they just don't think of it.

What do transsexual women do when offered the chance to bank sperm prior to starting hormone therapy? Limited evidence suggests that they usually take advantage of the opportunity to medical therapy that results in sterility. Dr. Joy Shaffer of Seahorse Medical Clinic in San Jose has been offering reproductive options to her patients since 1995. During that time, she offered sperm cryobanking to nine consecutive young, childless male-to-female transsexual patients, prior to beginning hormone therapy. Seven of the nine elected to bank sperm. Another of her patients stopped hormone therapy for three months in order to bank, and vet another patient had banked on her own before starting hormones. Childless transsexual women readily elect sperm cryopreservation when it is offered to them, or when they think of it themselves. Nor is it prohibitively expensive; the cost is typically \$50 to \$100 to store an ejaculate, with three suggested, and then about the same per year for storage.

For female-to-male transsexual men, the options are more limited and more expensive; but emerging technologies are rapidly providing additional choices. Transsexual men can presently undergo hormone-induced super-ovulation and ovum retrieval, in-vitro fertilization with donor sperm, and cryopreservation of the resulting embryos. These may subsequently be transferred to a female partner, or to a uterine surrogate. This technology is admittedly expensive, but is entirely routine.

A cheaper and more versatile reproductive option is cryopreservation of slices of ovarian tissue. These can obtained by biopsy, or at the time of oophorectomy. This is a technology that is quickly approaching the point of widespread applicability. The first human pregnancy resulting from cryopreserved ovarian tissue was actually reported back in 1986. Since then, we have learned a great deal about effective preservation techniques. Slices of cryopreserved human ovarian tissue now yield very high percentages of viable follicles when thawed after months of storage. Roger Gosden's group at the University of Leeds has successfully restored fertility to oophorectomized sheep by autotransplantation of cryopreserved ovarian tissue. I believe it is not unreasonable at this time to offer ovarian tissue banking to transsexual men undergoing oophorectomy or other abdominal surgery prior to hormone therapy, in the expectation that techniques for the routine use of this tissue are just over the horizon. The cost of cryobanking ovarian tissue should be comparable to the cost of cryobanking sperm.

If transsexual men and women are to exercise their reproductive options, then both they and their caregivers must be aware of those options. In my opinion, the best way to promote this awareness is to incorporate language about reproductive issues in the Standards of Care of HBIGDA, the Harry Benjamin International Gender Dysphoria Association. As many of you know, the Standards of Care are being revised this year, for the first time in seven years. This would be an ideal opportunity to add language addressing the reproductive needs of transsexual patients.

Unfortunately, this goal will not be easy to achieve. The Task Force to revise the Standards of Care, chaired by Dr. Stephen Levine, is currently preparing its final draft of the new Standards, to be submitted to HBIGDA members for approval. I was one of the seven outside consultants allowed to preview, and comment on, the next-to-final draft. Although I am not allowed to tell you what was in the draft I reviewed, I can tell you what was not in it — there was no language addressing reproductive concerns. In my comments to Dr. Levine, I proposed language for a section on reproductive issues, including the following statement:

Both the mental health professional recommending hormone therapy, and the physician prescribing such therapy, should discuss reproductive options with the patient, prior to the start of hormone therapy.

Although I feel this language is uncontroversial, Dr. Levine tells me that it will not be included in the final draft.

Unless language such as this is added by the membership, the current double standard will continue. Transsexual persons will continue to be the only group whose caregivers recognize no obligation to provide reproductive counseling prior to medical therapy that results in sterility. The membership of HBIGDA has the power to change that, by inserting the language the Task Force rejected. If you agree that the double standard must end, the time to act is now. Write to Dr. Bean Robinson, the Executive Director of HBIGDA, and to Dr. Stephen Levine, and express your concern about addressing reproductive issues in the Standards of Care. I have provided an information sheet containing proposed language for a section on reproductive issues, along with the addresses of Drs. Robinson and Levine, to anyone who is interested. By speaking up, we can work together to craft Standards of Care that better meet the reproductive needs of transsexual patients.

On March 1, 1997, Dr. Lawrence proposed the following language concerning reproductive issues to the Task Force to Revise the Standards of Care.

Preservation of Reproductive Options In Persons Receiving Hormone Therapy

Hormone therapy will induce temporary sterility in many patients. Permanent sterility may result from prolonged hormone treatment, and will definitely result if gonadectomy is performed in connection with genital surgery.

Many cases are known of persons who received hormone therapy and subsequent sexual reassignment, without having previously had children, who later regretted their inability to parent genetically-related children.

Both the mental health professional recommending hormone therapy and the physician prescribing such therapy should discuss reproductive options with the patient prior to the start of hormone therapy. Genetically male patients, especially those who have not already reproduced, should be informed about sperm-preservation options, and encouraged to consider banking sperm prior to hormone therapy. Genetically female patients do not presently have readily-available options for gamete preservation, other than cryo-preservation of fertilized embryos, but they should be informed about reproductive issues, and about this option. When and if other options become available, these should also be presented.

Persons wishing to comment on this proposed language, or on reproductive issues in the Standards of Care generally, may contact:

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aegis (e'jis), n. 1. in Greek mythology, a shield or breastplate used by Zeus and later, by his daughter Athena; hence, 2. a protection. 3. sponsorship; auspices.

Medical Advisory Bulletin

August, 1997

Polycystic Ovary Syndrome in FTM Transsexual Persons

The Problem

Polycystic Ovary Syndrome (PCOS) is a medical condition that may affect as many as one-half of FTM transsexual persons. The symptoms of PCOS may include hirsutism (in the absence of androgen treatment), irregular or absent menses, dysmenorrhea (painful menses), obesity, and, rarely, true virilization. Persons with PCOS are at increased risk for endometrial hyperplasia (overgrowth of the lining of the uterus), for endometrial cancer, and for breast cancer.

Advisory

Persons with symptoms of PCOS should consult their physicians concerning possible diagnostic studies. The usual treatment for PCOS is administration of progesterone, with or without estrogen — therapy which some FTM transsexual persons might find undesirable. In some cases, the diagnosis of PCOS might constitute a justification for hysterectomy and salpingo-oophorectomy (surgical removal of the uterus, tubes and ovaries). Patients with PCOS should discuss treatment options and side effects with their physicians.

Discussion

In PCOS, both the ovaries and the adrenal glands produce abnormally high levels of androgens, including testosterone and androstenedione. The exact cause of this over-production of androgens is unknown, but it is dependent upon chronic high level of luteinizing hormone (LH). Some of the excess androgen is converted to estrogen in the body, resulting in high levels of estrogen as well. Since persons with PCOS do not usually ovulate, these high estrogen levels are not opposed by progesterone. The unopposed estrogen effect may cause endometrial hyperplasia, and an increased risk of endometrial cancer, as well as breast cancer, in some individuals. In some cases, PCOS may be an inherited disorder.

The ovaries of persons with PCOS typically contain multiple cysts, and may be enlarged; this is the origin of the syndrome's name, although not its most essential feature. Polycystic ovaries may be detected during routine pelvic examinations, by ultrasound examination, or during abdominal surgery. If sufficiently enlarged, polycystic ovaries may rarely become symptomatic in themselves.

Although many FTM transsexual persons with PCOS may welcome the hirsutism and menstrual changes that can be part of the syndrome, the accompanying chronic high estrogen levels may create problems, particularly as they affect body habitus and the uterus. Persons with symptoms of PCOS should seek medical attention.

Source

Balen, A.H.; Schachter, M.E.; Montgomery, D.; Reid, R.W.; & Jacobs, H.S. (1993). Polycystic ovaries are a common finding in untreated female-to-male transsexuals. *Clinical Endocrinology*, 38(3), 325-329.

This document was formulated after consultation with physician members of the AEGIS Advisory Board

Polycystic Ovary Syndrome in FTMs by Jamison Green

Trans-positive health care reform

must include the acknowledgement

that our bodies deserve medical care

regardless of our gender identity.

According to Sheila Kirk, M.D., board certified gynecologist, from 1 to 5 percent of the natally female-bodied population is afflicted with the disease known as Polycystic Ovarian Syndrome (PCOS). However, 25% of FTM individuals have PCOS (FTM Newsletter, #36, March '97, page 5.)

In 70% of cases, PCOS is accompanied by elevated levels of a particular androgen released into the bloodstream by the adrenal glands: dehydroepiandrosterone. In more than 50% of cases, another male hormone from the adrenal, 11 beta hydroxy androstenedione, is elevated. These substances increase the risk of heart disease and hypertension. Combined with exogenously administered testosterone, the effects "could"

lead to serious lipid metabolism alterations and consequent heart disease." PCOS also increases the risk of ovarian cancers and uterine endometrial malignancy, and there is evidence of increased risk of breast cancer when PCOS is present.

PCOS is often characterized by obesity, and irregular, prolonged, or heavy menses, and some masculinization (voice pitch changes, temporal balding, facial hair growth, altered hair growth patterns on body trunk and about the genitalia and extremities, and distinct clitoral growth), but many people show no obvious symptoms.

Dr. Kirk recommends that all FTM individuals, prior to starting testosterone, have pelvic and/or transvaginal ultrasound to study the ovaries, and a blood test to determine possible elevation of the two adrenal androgens mentioned above. If PCOS is diagnosed, it is possible to treat the disease, sometimes using female hormones (estrogens), and until the transition process is begun (testosterone use initiated) it could be reasonable to treat the condition in the "normal" (for women!) manner. If the transition process is already begun, surgical removal of the uterus and polycystic ovaries may be advisable, even if genital reconstruction is not anticipated or is planned for the distant future.

However, it is not always easy for an FTM person to obtain treatments that some people believe are too frequently forced on women by a scalpel-happy medical establishment. Hysterectomy/oophorectomy (removal of the uterus and ovaries) is an expensive procedure, especially in cases where an abdominal incision is necessary (vaginal entry is not always possible) and a hospital stay of several days is required. If an FTM person is transitioned or cross-living and insured as a man, his insurance company is likely to balk at the revelation of his female body parts that need attention. Ironically, if the FTM individual is known as a female, doctors may be reluctant to remove reproductive organs, fearing that the person may want to have a child someday. And if the person has revealed his FTM identity, doctors may be reluctant to perform a hyster-

ectomy/oophorectomy because they see the procedure as assisting in the masculinizaton process, and they may not wish to be involved in treating medically what they view as a psychiatric condition. Or insurance companies may deny pay-

ment for the procedure if they deem it associated with sex reassignment, which is almost always (in the US) excluded from coverage. All of these situations have been known to happen.

Trans-positive health care reform must include the acknowledgement that our bodies deserve medical care regardless of our gender identity. PCOS is not a psychiatric condition, and just because an FTM person has the disease does not mean he should not be treated for it with every consideration given to relieving both the physical distress caused or threatened by the disease, and the emotional distress caused by being male-identified and living in a female body. Until such reforms are in place, each FTM person must negotiate his own solution to the PCOS problem. With the help of understanding and supportive physicians, we may someday win the battle for trans-inclusive health care.

Please let us know how you have fared in getting necessary medical attention for "female problems" so we can keep a database that may be helpful someday in resolving our health care dilemma.

Office Care of Transgendered and Transsexual Clients

The very presence of transgendered and transsexual persons can have an impact on other clients and office staff. What should a clinician know about how to address the client, how to prepare billing records, what to tell receptionists and nurses, and which restroom to direct the client to? In other words, what is proper office protocol?

In addition to needs caused by or related to their gender issues, transgendered and transsexual clients suffer from the same range of physical and mental illnesses and conditions that plague the rest of mankind, and their needs for treatment are the same as any other patient. Surprisingly, many transsexuals and transgendered individuals are routinely refused treatment, even when gravely ill - and when they do obtain treatment, their gender presentation may lead to a lesser standard of care than they would otherwise have received. In fact, the focus can easily change from their medical needs to their manner of dress, even under emergency conditions. Confidentiality considerations, professional ethics, and simple human decency are too-often forgotten as what started out as a request for treatment quickly becomes the Ricki Lake Show. Staff may ignore the client, ask rude questions, make their moral and religious views known, or converse loudly and publicly about the individual, using disparaging terms (Jonas, 1976). In extreme cases, the medical needs of the individual may be ignored, even to the point of death (Bowles, 1996).

Ideally, the client should be looked at in a holistic manner, with the transgender or transsexual issue factored into treatment in the same way as other physical and behavioral characteristics would be. This does not mean the clinician must specialize in transsexualism in order to treat transgendered clients. Often, the client will seek treatment not directly related to his or her gender issue — for a cold, for example, or because of heart disease or diabetes. It's important to consider symptoms in light of gender-related treatment the client may be receiving — for instance, hormonal therapy. At other times, the client may be seeking masculinizing or feminizing medical procedures, or presenting with problems related to such treatments. Some clients will have the bulk of such treatments behind them, and some will be just starting out.

It does not require any special knowledge or training about gender dysphoria to set a bone broken in an automobile accident or fill a tooth when that bone or tooth happen to be attached to an individual who challenges our notions of what a man or woman is. A little common sense in the treatment setting can go a long way. However, individuals with gender identity issues have special needs related to being transgendered. For example, those on hormones need to have their blood levels monitored periodically, and both female-to-male and male-to-female postoperative clients are at risk for osteoporosis and should be on small doses of hormones; additionally, they should have periodic bone density measurements. Many of their medical procedures have to do directly with altering their bodies: hormonal therapy, electrolysis, breast implants or breast reduction, facial plastic surgery, and sex reassignment surgery, and aftercare of such procedures.

Many transgendered and transsexual individuals lead middle-class lives, but many others don't. Individuals who live on the street will be likely to have issues with sexually communicable diseases, including HIV, and alcohol and substance abuse problems, and will be at risk for physical abuse, malnutrition, hepatitis, and other conditions. There may also be negative effects from liquid silicone which male-to-female individuals have had illegally injected in order to create "instant curves."

Other clients and office staff can be impacted by transgendered and transsexual clients. The two most common reactions are curiosity and disgust. In most situations, these feelings will be kept private, but it's possible that something may be said. Staff should of course be instructed to behave in a professional manner. The situation is a bit more thorny when other clients are involved. A nontransgendered client who is acting grossly inappropriate can be asked to leave the office or moved to the front of the line and hustled into an examination room. If the situation in the waiting room becomes tense, either the transgendered client or the client with problems with him/her can be shown to a private area. It's unlikely that there will ever be a need for this, but it doesn't hurt to have a contingency plan.

It's more likely that office staff will communicate their personal feelings in a passive-aggressive manner, for instance, by loudly calling a client dressed as a female by a male name, or vice-versa. The former "Mrs. Smith" will assuredly be highly embarrassed by being called by that name. Medical records should be kept current, reflecting the client's proper name and gender presentation. A brief in-service will teach staff proper procedures and make it clear when a staff member is being deliberately offensive.

There is a protocol for name and pronoun use. It is based on common sense: transsexuals and transgendered clients who have permanently crossed gender roles should be addressed in the same way as other individuals of that gender. If a client presents sometimes as a male, and sometimes as a female, s/he should be addressed in public according to how s/he is dressed. In private, you should use the client's preferred name and pronouns, and ask what name to use for mailings and telephone calls. If you're not sure which name or pronoun to use, it's not considered impolite to ask.

It's important to learn about other resources, so clients can be referred to other professionals. Fortunately, there are a variety of materials which can help to bring yourself and your staff up to speed on transgender and transsexual issues. AEGIS, the American Educational Gender Information Service, P.O. Box 33724, Decatur, GA 30033-0724 [770-939-2128; aegis@gender.org] can provide you with referral information and with educational materials.

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