Gender Dysphoria + Neurotoxicity + Spinal Cord Injury:

Meeting the Needs of a Complex Patient

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CASE STUDY: **80 y/o, married (58 years), Caucasian, transgender woman with history of Afib, cardiac pacemaker, HLD, PVD, DM2 c/b polyneuropathy and sleep apnea. Veteran was admitted to community hospital after fall on stairs (no LOC), resulting in C7-T1 fracture dislocation and C3-T3 posterior instrumented fusion. Veteran was transferred to VA SCI/D Center for evaluation of possible rehabilitation.**

PRIOR TO SCI: Veteran disclosed to wife during their 40th year of marriage about gender dysphoria, recounted as teen digging through laundry, donning mother's full slip and admiring. Wife was shocked because "he was always my big, 6'6" strong hero". She also shared their children were adopted because inability to conceive due to low sperm count.

- After wife told, patient began periodically cross dressing. Wife considered divorce, but decided against because maintaining family was priority.
- Veteran began participating in LGBTQ get-away weekends a couple times a year. Wife was aware, but she did not want to know any details.
- Last six years, patient began purchasing expensive lingerie to wear to bed. Wife tolerated because "I knew my eyes would be closed while sleeping".
- Veteran purchased artificial breasts that adhere to skin, but bonding lessened over time, so began using **industrial strength spray adhesive, 3M-777**. Adhesive remained on skin, turn black over time, and wouldn't wash off. Wife frequently cleaned with acetone the residuals off of the carpet, upholstery, and hard surfaces.
- Veteran purchased beautiful, expensive clothing online to wear during the day and the silk fabric always puckered from contact with adhesive. Wife rationalized the purchases as "his" hobby as acceptable because "he" had never spent money wastefully.
- Later, wife researched MSD online and immediately urged discontinuation because already had been using for a year. Veteran did not change behavior.
- Stepwise functional decline was observed, such as inability to read newspaper though previously avid reader. The inability to operate the TV remote became apparent though had always been main controller. Paying bills was suddenly problematic though historically prided self in financial management. Veteran even called bank repeatedly to report system error though none existed, would pay same bills more than once, locked self out of smart phone x3, and even when downgrade to flip phone, could not operate. Fine motor dexterity deteriorated with remarkable decline in penmanship.
- Toxicity worsened to the point of bowel and bladder incontinence, unsteady gait, loss of balance, full body tremors, itching, dysphagia, lower extremity edema, and insomnia.
- During the week prior to SCI, wife discovered Veteran wide awake at 2:15 a.m. with music blaring, all lights on, and exhibiting odd behavior. This resulted in subsequent brief inpatient psychiatric stay; SI/HI denied.
- Still, Veteran had told wife that she had considered throwing self down the stairs and did so 4 days later. Veteran

POST INJURY: **Quadriplegia C6 AIS D; 322-day SCI/D inpatient stay**

STAFF INVOLVEMENT: Multidisciplinary integrative care (i.e., physiatry, nursing, psychology, recreational, physical and occupational therapy, social work, pharmacology, dietetics, healthcare trainees, Veteran, and family) and myriad of consultations (e.g., transgender care team, psychiatry, ethics, palliative, regional counsel)

CHALLENGES:

(1) COGNITIVE COMPROMISE: Toxic exposure plus UTI induced delirium secondary to refusal of bowel care; *"Why do I need to go if I am not eating?"* Veteran overly focused on weight gain, began eating only salads and later refusing meals, so PEG placed. Subsequently, Veteran exhibited daytime somnolence, declined oral hygiene care, refused OT/PT therapies, barely opened eyes and responded with only minimal nodding when staff tried to conversate. Veteran was not oriented to time passage nor accurately recalled services offered. Month 7: Mirtazapine, Olanzapine & B12 initiated and Gabapentin decreased.

(2) **GENDER DYSPHORIA:**

- Veteran initially preferred male pronouns, but months later requested to be called by female name and pronouns. Staff asks if allowed to address Veteran by her preferred name and pronouns since POA was activated. **Per VHA Directive 1341, "It is VHA policy that Veterans must be addressed based upon their self-identified gender identity; the use of Veteran's preferred name and pronoun is required."** MD, Psychologist, and unit management determined preference aligned with said directive, was not deemed a life-threatening healthcare decision, and no different than someone asking to be called Bob when Robert is legal first name.
- Veteran asked about Gender Affirming Hormone Treatment and consultation made to Transgender Health Care physician. Conclusion: Estradiol is associated with an increased risk of clotting though some mitigation due to use of apixaban. Concerns include patient's age, atrial fibrillation, overall debility and history of pulmonary emboli. Transdermal estradiol advised for GAHT in patients over 50. MD requested to discuss with patient and spouse, but Veteran asked to defer.
- With aid of SCI/D Assistive Technology staff, Veteran participated in virtual VA LGBTQ support group. The group is designed for persons who identify themselves as sexual or gender minorities, or those interested in gaining information about LGBT individuals who have served in the military. Goals include fostering beneficial interpersonal skills, improving insight, and building coping strategies for finding one's place in the world. Group facilitators became concerned because she minimally participated in discussions and often left sessions early. SCI/D staff advocated on her behalf because Veteran consistently reported value in attending.
- Some staff conjectured that she was refusing bowel care because of assumed history of sexual trauma. This bias was addressed along with more comprehensive education. SCI/D Psychology met with individual staff, generated division-wide email series, referenced VA online trainings, and posted reminders in patient room. Strong emphasis was placed on gender variance not being a mental health disorder. Staff were taught that nearly 10,000 self-identified patients are currently being served by VA and likely many more not yet comfortable enough to disclose.

REDEFINING REHABILITATION: Because Veteran increasingly refused more cares and therapies, interdisciplinary team identified her most frequently expressed priority (i.e., living authentically as a female). Recreational therapy (RT) initiated make-up application training and accessing feminine clothing to promote choice. Veteran initially took passive role though with time made stepwise improvement in participation. Veteran's wife consulted with team members and concluded, **"I have my wife hat and my POA hat; this is about what makes him happy. I am not a lesbian, so this is really hard for me. But I want to be his POA, which is doing what he wants, even when that's different."** Of note, some staff mistakenly conveyed that RT was the reward for cares compliance; thus, there was need for staff education to differentiate between reinforcement vs. punishment. OT later diligently attempted UE skill transfer makeup tool to eating utensil though Veteran remained resistant. Psychology/PT began conducting collaborative sessions with SMART goals regarding NuStep, UE and LE strength testing, and ROM. Veteran began making notable gains.

DISCHARGE: Initial barriers to placement included associated stigma and needed level of care. **Veteran was eventually admitted and thriving in LTC**, attending activities, eating evening meals in cafeteria and socializing. Activities Director did her hair and makeup every morning for three months until admitted to a local hospital for pneumonia and UTI. Veteran fell out of bed, striking her head on the floor while there. Imaging WNL. She was discharged back to LTC two weeks later. She reiterated to her wife how painful the fall had been and that afternoon **Veteran died peacefully in her sleep. Subdural hematoma suspected**.

CONCLUSION: **Complex cases often involve high resource utilization, poorer than expected outcomes, and system strain, as well as imposed burden for those involved. Collaborative care practices are essential within the ever-changing treatment milieu for each unique SCI/D Veteran, not only due to physiological status changes, but with consideration of other mediating factors. Utilizing a coordinated and holistic approach creates a viable communication infrastructure that keeps stakeholders informed, as well as creates more synchronistic decision-making and flexibility in meeting the needs of each SCI/D Veteran.**

REFERENCES: Available upon request.