

CHRONIC KIDNEY FAILURE AND SEXUAL FUNCTIONING

Joyce M. McManus

BA, MDiv, BSW, RSW

SEXUALITY DEFINED

- A deep pervasive intrinsic aspect of the total person
- Sum of the feelings and behaviours of one's sexual identity
- Is an intimate form of communication that helps relieve suffering and can lessen the threat to one's personhood in the face of life-threatening illness
- A complex process, coordinated by the neurologic, vascular and endocrine systems

FACTORS INFLUENCING SEXUALITY

- Age and stage in life
- Biology and genetics
- Culture/Ethnicity
- Experiences
- Health Status
- Religion/Spirituality
- Stereotypes
- Stressors

INTIMACY

- The sharing of identity, mutual acceptance, closeness, reciprocal rapport
- More closely linked to communication than to sexual functioning
- Heart to heart understanding of the other
- Intrinsic to the sense of self
- When one feels intimately loved, nurtured, cared for and supported, the person is likely to be able to cope better with life's challenges

Prevalence

- Before dialysis, in patients ages 20-60 years, sexual dysfunction was 9%
- With dialysis, sexual dysfunction rose to 60-70% in both male and female patients in this age group

SEXUAL HEALTH AND KIDNEY DISEASE

- Men and women with kidney failure experience changes in their sexual functioning
- Changes affect their interest in sex as well as the ability to have sexual encounters
- Somatic and emotional reasons for these changes in sexual health

Sexual Dysfunction

- Sexual dysfunction on peritoneal or haemodialysis is not so much due to erectile failure but largely due to loss of sexual interest, subjectively ascribed to fatigue. (A.W.F.T. Toorians, E. Janssen, E. Laan, L.J.Giltay, P.L. Oe, A.J.M.Donker and W. Everaerd. Chronic Renal Failure and Sexual Functioning, **Nephrology Dialysis Transplantation** (1997) 12:2654-2663.
- Study found that in women on peritoneal or haemodialysis, their decrease of sexual desire was linked to fatigue

SEXUAL RESPONSE CYCLE

- **Masters and Johnson** (1970's): excitement, plateau, orgasm, resolution; linear model for men and women
- **Helen Singer Kaplan**: desire, excitement, orgasm; linear model with 3 distinct phases
- **Rosemary Basson**: female response cycle focused on thoughts and feelings and then sexual arousal occurs; sexual satisfaction can be an orgasm or seeing one's partner enjoying the sexual experience; a circular model

Common Side- Effects of Kidney Failure:

Interruption of the sexual response cycle

- **Men** may lose the ability to have an erection and/or maintain an erection (ED); increasing difficulty being orgasmic
- **Women** may have difficulty becoming aroused and having an orgasm
- **Caution:** women should not become pregnant; birth control essential

SOMATIC REASONS

- Severe malnutrition, vitamin and zinc deficiencies in the early days of dialysis; relatively rare today
- Uraemic toxins, and “middle molecules” not convincingly implicated in sexual problems
- Disturbances of reproductive hormones and prolactin in the past; now replaceable but little improvement in sexual health issues
- Atherosclerosis accelerated in CKF; with kidney transplant there is rapid improvement in sexual functioning

SOMATIC REASONS (con't):

- Uraemic neuropathy is slowed by dialysis, but does not improve sexual functioning
- Several drugs used in the past for CRF may have caused sexual dysfunction; now replaced with more modern drugs but has not reduced sexual dysfunction
- Anaemia causing fatigue may cause lack of interest in sexual activity
- Pre-existing illnesses/medications interfere with the sexual response cycle

SOMATIC REASONS (con't):

None of the above mentioned mechanisms has satisfactorily explained the high incidence of sexual dysfunction in patients with CKF

PSYCHOLOGICAL REASONS

- How patient feels about her/himself
- Anxiety, depression, worry when faced with kidney disease
- How well communicate with partner about feelings
- Feeling of embarrassment and guilt if sexual problems occur
- Pregnancy for women with CKF
- Fear of harming the dialysis access or transplanted kidney
- Fear of dying from CKF
- ***Fearful of asking questions of the health care providers***

BARRIERS TO SEXUAL HEALTH COMMUNICATION

- **Patient:** discomfort bring up the issues; fearful of judgement regarding sexual orientation/sexual practices/age/race/ethnicity/religion/language, partner status
- **Health Care Provider:** assumptions and sexual experiences, lack of knowledge and experience talking to patients about sexual health issues, discomfort, embarrassment, lack of confidence, whose responsibility is it on the team to address these issues?
- **Systemic Issues:** lack of time, privacy, resources, literature, cost of treatments for dysfunction, not included in assessment forms

THE BETTER MODEL

- ***Bring up the topic***
- ***Explain that sex is part of Quality of Life***
- ***Tell patients that resources are available to address their sexual concerns***
- ***Time the intervention***
- ***Educate patients about possible sexual side effects of treatment***
- ***Record briefly***

PROFESSIONAL RESPONSIBILITY

- Whose responsibility is it on your team to discuss sexual health?
- Know the effects of disease, medications, CKF, dialysis, transplant on the patient
- Personal information re partner, sexual orientation, sexual health issues
- Learn ways to easily talk about sexual health issues with patient/partner; make “the sex talk” a normal part of your assessments and follow-up with patients
- Privacy and permission of patient
- Have prepared materials to give to the patient re sexual health
- Know community resources for referrals
- Know yourself and your personal sexual biases

BETTER

Bring up the topic:

- Find a private place
- Ask patients' permission to talk about the sexual side effects of CKF when doing assessments and health teaching:

“Many people with CKF say that they experience changes in their sexual health. (***normalize changes***) I would like to talk to you about some of those changes and how you might manage them. Is it alright if I talk to you with your partner present? Or would you prefer I talk with you alone?” (***respecting privacy***)

BETTER

Explain that sex is an important part of Quality of Life:

- “Sexuality is an important part of life. When individuals are not feeling well, sexual abilities and desires may change for both the person who has the illness and for their partners. Some people find that difficult to talk about. Our team wants you to know that your sexual health issues are an important part of the health care we provide you. We will be asking you periodically about concerns you may have regarding sexual health.”

BETTER

- Since you started dialysis or transplant, have you noticed changes in your sexual health? Could you share some of those that you are experiencing ?
- Before your CKF or transplant, what was your sexual functioning like?

BETTER

Tell the person that resources are available to address their sexual concerns:

- I will give you a pamphlet that outlines some of the changes you may experience that you (and your partner) can read at home
- We have social work services on our team. They would always be willing to meet with you (and your partner) to further discuss your concerns.
- There are other professionals that we can put you in touch with as well if you so wish.

BETTER

Time the intervention:

- At the initial intake interview, include sexual health issues in the overall assessment: role of the illness and medications on sexuality
- Periodically ask how the person is coping with sexual changes
 - “I remember at your last visit you were talking about your lack of desire. How are you managing that change? Did you try any of the suggestions that we talked about last visit?”

BETTER

Educate people about the sexual side effects:

- Explain how the disease, the treatment and the medications contribute to the person's sexual health
- Take into account other disease processes and other medications they are already on that may also contribute to sexual dysfunction

BETTER

Record briefly:

- If it is not recorded, it did not happen
- Record: “Explained side effects of treatment, including sexual side effects” “Patient states he is experiencing less sexual desire than a month ago. Provided him/her with suggestions and referral possibilities” “Patient and his partner were referred to social worker with their consent regarding relationship/sexual issues.” “ Suggested that patient contact her gynecologist about her vaginal dryness.” “Asked patient to talk to his urologist regarding erectile dysfunction at his next appointment.”

OTHER SUGGESTIONS

- Invite the partner (if present) to give her/his perspective on changes
- **Normalize** anxiety, depression/loss and stress and how these may affect sexual functioning:

“Those are feelings that many of our patients/partners experience.”

- Assessing **communication/providing resources**:

“Have you talked with each other about those feelings of fear/despair? It might be helpful to talk to our social worker about those emotional concerns. I could make a referral for you.”

“Because of your fatigue and low sexual desire, you could consider cuddling, snuggling, holding hands, gently touching without the expectation of sexual intercourse.”

SEXUAL EDUCATION

- Empower patients to take control of those things that they can control-healthy eating, exercise, faithful taking of medications, hobbies for pleasure, good self-care
- Teach about fistula, graft, incision, peritoneal catheter and how sexual activities can be adapted as to not compromise these areas
- Educate about fertility issues
- Encourage return to former pleasurable hobbies, activities, couple/social activities that are enjoyable

SUGGESTIONS FOR SEXUAL DYSFUNCTION

- **Female:** vaginal dryness-longer foreplay, vaginal lubricants (ie. KY, Astroglide), vaginal moisturizers (ie. Replens); HRT, Estrin, estrogen vaginal creams; regular sexual stimulation (intercourse, vibrators, dildos); EROS-CTD (clitoral therapy device)
- **Male:** erectile dysfunction-longer manual stimulation, erotica, medications for ED (ie. Levitra, Viagra, male hormones, injectables, urethral cream), surgery, penile pumps, penile implants; advise to not use pumps from the local sex shops-see urologist
- Lack of desire: start with touching, cuddling and desire may follow
- Individual/Marital therapy: Family Services, EAP, social workers, Family Health Teams

SEXUAL DYSFUNCTION (con't)

- Suggest follow-up with family physician, urologist, endocrinologist, gynecologist, psychiatrist, counsellor/social worker
- Know who provides sex therapy in your community (qualifications?)

SEXUAL SELF-CARE FOR PATIENTS

- Take extra care with grooming: when you look good, you feel better
- Try to not think of sexual intercourse as the only sex act when there is limited sexual desire or energy; find other ways to give and receive pleasure that do not require as much energy but is enjoyable to both partners
- Don't ignore the sexual health challenges: raise your concerns with your health care team members
- Keep in mind overall emotional, physical and spiritual self-care

PROFESSIONAL DUTIES

- Professionals ***must initiate*** the conversation re sexual health
- Know you own prejudices, biases and sensitivities
- Know your professional boundaries laid out by your College
- Keep firm personal boundaries in place
- Learn to deal with sexually suggestive patients:
 - “I could lose my license if I met you for a drink after work.”
 - “What works for me in my life will be different than what may work for you. We are here to deal with your sexual health issues today.”
 - “I don’t appreciate the way you are talking to me. Please refrain from using those words or making those comments.”

PROFESSIONAL RESPONSIBILITIES (con't)

- You do not have to have all the answers. Refer to others:
 “I’m not sure but I will do some research and find out for you for your next appointment.”
- Know your limitations. Know your vulnerabilities.
- Debrief with colleagues/manager
- use your EAP provider for emotional self-care

RESOURCES

- Community resources: physicians, counselling agencies, sex therapists
- Dr. Ann Katz book: ***Sex When You Are Sick***
- National Kidney Foundation: ***Sexuality and Kidney Disease***
- The Kidney Foundation of Canada: www.kidney.ca/sexuality

Sexuality and Chronic Kidney Disease article –could be the foundation of a pamphlet for patients and their partners, ***Living with Kidney Disease Manual*** (cpt on emotional and sexual issues)

REMEMBER

“People with kidney failure can have healthy marriages and meaningful relationships, They can fall in love, care for families, and be sexual. Staying intimate with those you love is important. It’s something everyone needs. Many people think that sexuality refers only to sexual intercourse. But sexuality includes many things, like touching, hugging, or kissing. It includes how you feel about yourself, how well you communicate, and how willing you are to be close to someone else.”

Website-National Kidney Foundation: *Sexuality and Kidney Disease*