

Let's Talk About Sex: Understanding Social Workers' Approaches to Discussing Sexuality With CKD Patients

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A review of the literature suggests that patients do not typically initiate conversations related to sexual function. Our small exploratory pilot study set out to understand the barriers social workers face when initiating discussion of this quality-of-life issue. Forty-two members of the Canadian Association of Nephrology Social Workers responded online to a short survey pertaining to their discussions with CKD patients around sexual function. The majority of respondents felt they had a working knowledge of CKD and sexual function. Despite most reporting some knowledge and comfort in discussing the issue, only half said they initiate the discussion. This article describes barriers to the discussion of sexual function and presents implications for social work practice.

INTRODUCTION

The nature of chronic kidney disease (CKD) strongly influences sexual function (Rozenman et al., 1990). The literature suggests that sexual function is compromised among both male and female patients with CKD (Arslan et al., 2002; Hickman, 1977; Katz, 2006; Peng et al., 2005; Steele et al., 1996). CKD also plays a significant role in the lack of development of sexual function in men and women (Turk et al., 2001). Physical and psychological factors impact patients' sexual function. Physical factors include pain, fatigue, hormone imbalance, uremia, anemia, leg cramps, medications and other medical issues (Arslan et al., 2002; Hart & Thomas, 2007; Katz, 2006). Psychological factors include anxiety, depression, sleep disorders, body image and change of role or identity within the family (Arslan et al., 2002; Hart & Thomas, 2007; Katz, 2006). In terms of sexual complaints, men report a high incidence of erectile dysfunction, reduced libido, lack of desire and orgasm complaint (Arslan et al., 2002; Katz, 2006). Women report reduced libido and lubrication, orgasm complaints, pain during intercourse and lack of pleasure (Katz, 2006).

Some studies suggest the different types of dialysis (e.g., hemodialysis vs. peritoneal vs. nocturnal) do not play a role in the degree of sexual dysfunction a patient may have (Katz, 2006; Steele et al., 1996). Another study found that of 249 women aged 23–65 with CKD, hemodialysis patients had a five times greater risk of having sexual function problems than peritoneal dialysis patients (Kettas et al., 2008).

It appears that patients on dialysis have more sexual difficulties than patients who are pre-dialysis or who have been transplanted (Katz, 2006; Steele et al., 1996). The prevalence of sexual function problems is estimated to run between 9% in pre-dialysis patients and 60–70% in men and women who are already on dialysis (Kettas et al., 2008). Several studies suggest that there is a significant link between sexual function and perceived quality of life for renal patients (Arslan et al., 2002; Hart et al., 1995; Ho & Fernandez, 2006; Steele et al., 1996). One study of 578 female patients on hemodialysis reported that the women with higher Index of Female Sexual Function ratings had significantly higher scores in physical functioning and mental health (Peng et al., 2005). Another study suggested that a lack of sexual activity is an important

determinant in a patient's self-assessment of quality of life (Steele et al., 1996).

In terms of the health care provider's role in disseminating information about sexual function, one study of successful transplant survivors showed that 70% of those interviewed said they wanted their health team to provide information on sexual function as it relates to CKD. However, only one-third of patients received this information (Hart et al., 1995). It is important to note that patients perceive their sexual health as important and worthy of attention (Ho & Fernandez, 2006). Of particular interest is the finding in one study that stated that the level of acceptance of patients' illness relates to their level of sexual function and satisfaction (Alleyne et al., 1989).

Research shows a pervasive tendency on the part of the nephrology health care team to avoid addressing the sexual function issue with renal patients (Arslan et al., 2002; Ho & Fernandez, 2006). To complicate matters further, the same tendency exists amongst the patients themselves (Arslan et al., 2002). Chronically ill patients, even those with a high level of awareness of their sexual function, rarely refer themselves to professionals for help (Hart et al., 1995). This reluctance to seek help places the responsibility on the health professional to initiate discussions around sexual function. Several studies suggest multiple reasons why health care professionals do not discuss sexual function with their patients (Arslan et al., 2002; Hart et al., 1995; Steele et al., 1996; Ho & Fernandez, 2006). These reasons include the belief that an in-depth understanding of sexual function and treatment methods is unnecessary (Hart et al., 1995), a lack of basic education about this subject as well as cultural, personal and religious factors (Hart & Thomas, 2007; Ho & Fernandez, 2006).

METHODS

The Canadian Association of Nephrology Social Workers (CANSW) is a national association comprised of 114 members from across Canada who hold either a bachelor's or master's degree in social work (or both) and provide social work services to CKD patients in a variety of settings. They are appropriately licensed or registered in accordance with the province or territory in which they reside.

Following the 2006 CANSW National Conference in Ottawa, Ontario, the organization developed a small working committee to address psychosocial issues facing renal patients and their families. The committee developed the following questions to be studied: How do CANSW members view their role with regard to discussing sexual function with renal patients? What are their current practices for doing so?

The committee completed a small-scale exploratory pilot study using a sample of CANSW members. There were 42 respondents: 37 females and 5 males. (At the time, there were 100 female and 12 male CANSW members.) The respondents' mean age was 46.4 years with a range of 27–65 years. As CANSW does not keep age data, it was not possible to know the ages of all potential respondents. Respondents varied in years of nephrology social work practice from 0.25 to 24 years. The years of nephrology social work experience was an average of 9.2 years among respondents, compared with 6.3 years among CANSW's general membership. The patient population areas served by the respondents varied and reflected the major areas of nephrology, including predialysis, peritoneal dialysis, hemodialysis and transplant. The majority of respondents (77%) worked within multiple nephrology populations, which is also true of the entire membership.

We used an online software program (<http://www.surveymonkey.com>) to design a 16-question survey to investigate CANSW members' views regarding their role in discussing sexual function with people with end-stage renal disease (see Appendix A). The questions were both open- and closed-ended, allowing respondents to check appropriate answers provided or offer their own explanations. Descriptive scales were employed to allow respondents to rate themselves on specific variables related to discussing sexual function, including comfort, knowledge and barriers to communication (e.g., "very," "somewhat," "not at all").

RESULTS

Research Question 1: How do CANSW members view their role with regard to discussing sexual function with renal patients?

Social workers were asked if they felt it was their role to discuss sexuality with their patients. All 42 participants indicated that it was their role, and the majority (92.9%) felt it was their role in collaboration with other health care professionals including the nephrologist, nurse and sexuality consultant, as available.

Research Question 2: What are CANSW members' current practices for discussing sexual function with renal patients?

Respondents were asked if they initiated discussions regarding sexuality with their CKD patients. Slightly more than half (52.4%) said that they initiate this discussion with their patients. Of those respondents that initiate these discussions, 44.4% of those do so "occasionally." Zero respondents indicated they do so routinely.

Table 1 highlights a number of reasons why nephrology social workers do not initiate discussions around sexuality, including lack of knowledge, privacy, personal discomfort, perception of patient's discomfort and privacy concerns.

Table 1

Reasons Why Nephrology Social Workers Do Not Initiate Discussions Around Sexuality With CKD Patients (n = 65)

Reasons	Number of Respondents	Percent (%)
Lack of privacy	18	42.8
My discomfort	9	21.4
My perception of their discomfort	13	30.9
Lack of knowledge on my part	13	30.9
Other	12	28.5
Total no. of responses	65	

In terms of their knowledge and comfort level, while 9.5% (4) of respondents felt they had "a lot of knowledge," the greatest majority of respondents at 50% (21) reported that they had a "working knowledge" of CKD and sexuality. Three respondents (7.1%) indicated that they did not have any knowledge at all.

With regard to comfort level, the majority of social workers felt "somewhat comfortable" (31.7%; 13) and "fairly comfortable" (31.7%; 13) when it came to discussing the issue of sexuality with their CKD patients, while 4.9% (2) of respondents felt "not comfortable." One individual skipped this question.

In addition to knowledge and comfort level, several participants disclosed more than one reason why they don't talk about sexual function. Table 2 highlights the more common responses, which were categorized into themes based on the 11 additional "other" reasons. For instance, more than 50% indicated that they do not initiate discussions with their CKD patients around sexual function because their expectation is that the patient would bring up the issue if they felt it was important. They did not want to make the patient uncomfortable by bringing the issue up themselves.

Additional reasons included time constraints and having other priorities. One participant indicated that the nurse, who sees patients first in the nephrology clinic, initiated such discussions. Another respondent stated the nephrologists in that program didn't believe it was an important issue to discuss.

Table 2

Other Reasons Why Nephrology Social Workers Do Not Initiate Discussions Around Sexuality With Their CKD Patients (n = 12)

Reasons	Number of Respondents	Percent (%)
Lack of time	1	8.3
Other psychosocial issues take priority (e.g., financial concerns)	1	8.3
Patients do not identify it as an issue	6	50.0
Perception that it is not an issue for the particular population of patients respondent served (e.g., senior patients)	2	16.7
Topic addressed by other colleagues	2	16.7
Total no. of responses	12	

DISCUSSION

Given that there is a strong link between sexual function and renal disease (Rozenman et al., 1990) and that sexual health is significantly linked to quality of life (Steele et al., 1996), it is important to address concerns about sexual function with CKD patients both in their clinical assessments and treatment plans.

Our study showed a high percentage (47.6%) of nephrology social workers do not initiate discussions around sexual function with their patients. Reasons cited include lack of privacy, lack of knowledge, perceived discomfort and sexual function not being a topic raised by patients themselves. They felt it was often overlooked because of other pressing psychosocial issues and/or lack of resources and tools. Respondents were pleased that the issue is being addressed by CANSW and believed sexual function was a significant, worthy topic. The committee advised potential respondents that results would be considered to develop policies and guidelines for discussing sexuality with the CKD patient and a great majority (97.6%) felt that it would be helpful to have such policies/guidelines.

Half of the respondents had tools to help initiate discussions related to sexuality. The list of those resources and tools included medical literature, National Kidney Foundation literature (from both the United States and Canada) and Internet resources. Other disease-specific groups (e.g., cardiac, stroke and oncology) have also designed tools and strategies for coping with this patient care area. We can learn from these other professionals.

When is the best time to discuss this topic with patients? One suggestion was that sexual function be addressed in the pre-dialysis clinic. That way, patients can be made aware that sexual function may be a common concern for people with CKD and that the team is available to address any concerns they may have. Many pre-dialysis clinics were said to give patients a questionnaire to complete before their initial visit. It was suggested that sexual function be addressed in this questionnaire so that the nephrology team can be made aware of any issues from the beginning. In this way, the issue can be normalized early in the care process.

Respondents were asked for ideas on how to address this issue to allow for increased understanding and discussion with patients. Because many renal units have newsletters, one suggestion was to include information about sexual function in them. Another suggestion was to develop a questionnaire that included the questions about sexual function. Patients could answer as they wish and a private, individualized session could be arranged.

The busy environment of the hemodialysis unit, where 10–15 patients sit together and are dialyzed in one room, plays an obvious role discussing this sensitive subject. It would be interesting to compare how the issue is managed with peritoneal dialysis patients, who have individual clinic appointments versus hemodialysis patients where the next patient is often only an arm's reach away. On the other hand, renal social workers do discuss other sensitive subjects in the busy hemodialysis unit, such as advance directives and end-of-life care. There appears to be something more acceptable about discussing death than there is about discussing sexual function.

The study indicates that 92.6% of respondents felt that the discussion of sexual function with a patient is a social work role in collaboration with other team members, including the doctor, nurse and pharmacist. Each team member brings his/her specific expertise to the subject. Something this study did not touch upon is the perspective of patients' partners. Social workers are well-equipped to deal with intimacy and closeness issues that are so entwined with sexual function. Social workers can also take the role of providing education to other team members about the prevalence of problems with sexual function in CKD patients and the need for sensitivity.

Of the respondents surveyed, many indicated that they would like to use educational materials for encouraging discussion. They also look to other team members for guidance and support. Providing the means for private discussions and increasing knowledge, comfort level and access to tools for discussing sexual function is essential for these conversations with patients to take place.

We suggest that our attention as social workers needs to be directed toward increasing opportunities, comfort and knowledge around the topic of sexual function not only for patients, but also for ourselves as clinicians. As social workers, we often tackle harsh human realities. We need to view

the topic of sexual function and CKD patients as a routine aspect of our social work assessment.

LIMITATIONS

There are a few limitations to this study that need to be highlighted. First, while a significant topic, a dearth of research exists around CKD and sexuality, which made it difficult to provide a comprehensive literature review. Second, with a response rate of 37%, the small sample does not accurately represent CANSW as a whole population. Finally, the survey tool, designed by the researchers, was not tested for reliability or validity.

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Appendix A

CKD and Sexuality Survey

INTRODUCTION

The purpose of this survey is to determine current CANSW member practices when it comes to talking to our patients about chronic kidney disease (CKD) and sexuality. Your identity and answers will remain anonymous and confidential. Information received from the completion of this survey will be used to develop a protocol for CANSW members to use in future discussions with patients about CKD and sexuality.

1. Gender:

- Male Female

2. Age: _____

3. Number of years in nephrology social work: _____

4. Population served: (Check all that apply.)

- Pre-dialysis
 PD
 HD
 Home hemodialysis
 Transplant

5. Please rate the following:

How knowledgeable do you feel about CKD and sexuality?

- No knowledge Some knowledge Working knowledge A lot of knowledge Expert knowledge

6. Please rate the following:

How comfortable do you feel talking to your patients about CKD and sexuality?

- Not comfortable Somewhat comfortable Fairly comfortable Comfortable Very comfortable

7. Do you initiate a discussion with your patients about sexuality?

- Yes No

8. If yes ...

How often do you talk about it with them?

- Seldom Occasionally Frequently With every patient N/A

9. If no ...

Why don't you talk about it with them?

- Lack of privacy
 My discomfort
 My perception of their discomfort
 Lack of knowledge on my part
 Other (please specify)

10. What might help you to address the topic of sexuality with your patients?

11. Do you feel it's your role to talk about sexuality with your patients?

- Yes, it's my role
- It's my role in part, with collaboration from other professionals
- No, it's not my role at all

12. If not, whose role is it?

- Nephrologist
- Nurse
- Sexuality consultant
- Other (please specify)

13. This survey will be used to help develop some guidelines for CANSW members to follow when discussing sexuality with their patients. Would you find these guidelines helpful?

- Yes
- No

14. In the past, have you used any resources or tools for discussing sexuality with your patients?

- Yes
- No

15. If you have, what resources or tools have you used to discuss sexuality with your patients?

16. Do you have any additional comments/suggestions as to how this subject should be or could be addressed by nephrology social workers?
