Towards adequate care for sexual health and fertility in chronic kidney disease: Perspective of patients, partners and care providers

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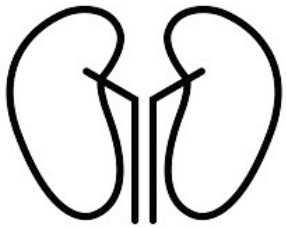
Part I

Sexual care & chronic kidney disease
The perspective of renal care providers



2. Discussing sexual dysfunction with chronic kidney disease patients; practice patterns in the office of the nephrologist.

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Introduction

Chronic kidney disease (CKD) is a great health issue worldwide. The estimated population prevalence exceeds 10% and is still rising[1]. Sexual dysfunction (SD) is a major and common problem in both men and women suffering from CKD[2]. Erectile dysfunction is present in 70% of the male patients; as well as reduced libido and difficulty in reaching an orgasm[3,4]. Female patients suffer from impaired vaginal lubrication, loss of arousal and desire, dysmenorrhea and difficulty in reaching an orgasm[4]. Sexual complaints in female patients are twice as frequent compared to the healthy population[3,5]. Patients undergoing renal dialysis report higher rates of diminished sexual desire and ability. In both types of dialysis the prevalence of SD measured is around 65% for men and 70% for women[6]. In case of hemodialysis the prevalence is even higher for women and rises up to 84%[7]. Kidney transplantation is known to cause improvement of sexual complaints, however the prevalence of SD after kidney transplantation still remains 46% in both men and women[6]. Immunosuppressive therapy needed after transplantation may cause impotence in men and loss of sexual interest in both men and women[8]. The etiology of SD in patients with CKD is caused by multiple underlying conditions including the uremic milieu, anemia, cardiovascular disease, CKD mineral and bone disorders, sex hormone disturbances, autonomic neuropathy, hyperparathyroidism and hyperprolactinaemia. Furthermore, the presence of SD is a result of side effects due to medication, comorbid illness (cardiovascular disease, diabetes mellitus and malnutrition) and psychosocial factors. Psychosocial factors include depression, anxiety, poor self-esteem, marital discord, social withdrawal, body image issues and fear of disability and death[2,4,5,9-11]. Several therapies have been used to treat SD in CKD; phosphodiesterase-5 inhibitors (PDE5i), intracavernosal injections, intraurethral suppositories, hormonal therapy en psychotherapy. However, the safety and efficacy of these interventions are poorly studied[4]. Sexual health is an important factor regarding quality of life (QoL), therefore the presence of SD contributes to the deterioration of QoL[12].This problem has been reported in both male and female patients suffering from CKD[13,14]. Patients with sexual dysfunction may experience higher levels of stress, anxiety and depressive mood. A quarter of patients with CKD fulfill the diagnostic criteria for depression[15]. Specifically in female patients a high association is present between sexual dysfunction and depression, the prevalence is increased fivefold when SD is present[16,17]. Furthermore, sexual complaints also have their effects on the social and married life.

Sexual dysfunction not only affects patients with CKD but their partners as well. Decreased partner satisfaction is a common problem[18].
Despite the growing body of evidence that SD diminished patients' health on several levels, only a few studies have been performed in order to examine to which extent renal care providers discuss these issues. Previous studies demonstrated that attention to and knowledge of sexual dysfunction from renal care providers is limited. Seventy-five percent of renal care providers were uncertain to which extent complaints of SD affected their patients. The majority of providers was hardly aware of the physiological and emotional problems patients had to endure[19]. Whether this is due to lack of awareness of the high prevalence and impact of sexual dysfunction on patients or by barriers in discussing sexual issues with the patient remains uncertain.
Due to the high impact of SD on patients' health, early detection is essential. The nephrologist can play an important role in the detection and counseling of SD due to their leading involvement during the whole process of disease. The aim of our study was to determine to which extent the nephrologists discuss the issue of sexual dysfunction with their patients suffering of CKD and the barriers towards discussing this subject.

Methods

Study design

Data for this cross-sectional survey were collected using a questionnaire. The sample consisted of all practicing Dutch nephrologists (N=318) who were members of Nefrovisie. This is a national agency of the Dutch Federation of Nephrology responsible for monitoring and supervising the quality of health care provided by nephrology departments. Since 6 addresses obtained from the agency were out of date, a total of 312 questionnaires out of 318 could be sent.

Instrument design and development

The questionnaire used for this survey was developed by the author (G.F.v.E.), a co-researcher (E.M.K.), an urologist-sexologist (H.W.E.) and a nephrologist (H.B.). The structure and design of the questionnaire was derived from questionnaires used in previous studies regarding sexuality and health care providers[20-24], with items based on issues identified by the authors and in literature. The survey was pilot tested by nephrologists and residents from the Leiden University Medical Centre department of nephrology (n=7). The approached representatives were asked to comment

on the content of the survey. No remarks were made regarding the content of the questionnaire, therefore no adjustments were made in the final questionnaire.

Survey and procedure

The questionnaire comprised of 50 items, containing multiple choice and open questions. The main focus was to reveal current practice and barriers regarding discussing sexuality and fertility issues. Furthermore, information was obtained about the current level of knowledge, the need for training and accountability for bringing up sexual dysfunction. Questions regarding to fertility issues were processed separately. The first sheet of the survey contained demographic questions and offered an opt-out possibility. A question could be answered regarding the reasons of withdrawal. Non-responders received a reminder letter 2 and 4 months, respectively, after the initial mailing. All questionnaires were processed anonymously. No formal ethical approval was needed.

Statistical methods

Acquired data were analyzed using SPSS release 20 (SPSS Inc., Chicago, IL, USA). Demographic information as well as answers to the survey were analyzed using frequency distribution. Hospitals of responders as well as non-responders were classified by population density of the area and type of hospital. With regards to population density, class I included areas with a population density of less than 283 citizens per km², class II included areas with 283-907 citizens per km² and class III had a population density of more than 907 citizens per km². The clinics were subdivided into certain types: tertiary referral centers and university hospitals versus district hospitals.

The Pearson chi-square procedure and Cochrane Armitage trend test were used to compare categorical data in regard to demographic information. For correlations between numerical data and demographic information a Mann-Whitney test was used. Outcomes were considered statistical significant if the two-sides P values were <0.05. For analyzing question 9 and 10 the answer “In less than half of the cases” contains the answers “never “ and “in less than half of the cases”, the answer “In half or more of the cases” contains the answers “the half”, “more than the half of the cases” and “always”. For analyzing of question 11 were the answers “ agree” and “totally agree”.

Results

Survey Responses

In total 51% (n=159) of the 312 questionnaires were returned. Out of the responses 106 surveys were completed (33.9%), 38 of the responders were not willing to participate. The main reason not to participate was lack of time (n=28), other reasons included: not practicing at the moment (n=5), not interested (n=2), retired (n=2), skeptical towards animosity of the participants (n=1) and not practicing as a physician (n=1). Almost ten percent (n=15) of the responding nephrologists were specialized in pediatric nephrology. Because the content of the questionnaire was remote from their patient population, their responses were excluded. Due to the fact no alterations were made after the pilot testing among nephrologist from the Leiden University Medical Centre, the responses of the pilot questionnaire were included (n=7). Eventually 113 of the 328 (34.5%) sent surveys were analyzed.

Demographics

A comparison was made between the demographic information of responders and non-responders. The gender of two non-responders was unknown, 310 nephrologists were used for comparison. More than 50% of the 310 nephrologists (53.5%, n=166) was male, 46.5% (n=144) was female. Of the non-responders, 106 nephrologists (53.8%) were male and 91 (46.2%) female. In the responders group was 61.9% (n=70) was male and 38.1% (n=43) female. There was no significant difference found between the distribution of gender between responder and non-responder (p=0.16).

Respondents' mean age was 47.2 years (± 8.3 SD), ranging from 33 to 62 years. Age of non-respondents was unknown. Male respondents were significantly older than female respondents (mean 50.2 *v* 42.2; $p<0.001$). The work place of 10 non-responders was unknown, resulting in 302 nephrologists used for demographic comparison. The majority of the 302 Dutch nephrologists (60.3%,n=182) are working in an area with a population density of more than 907 citizens per km². Eighty-five (28.1%) nephrologists were working in an area with a population density between 283-907 citizens per km² and 11.6% (n=35) in an area with less than 283 citizens per km². There was no significant difference found between the distribution of hospital location between responder and non-responder (p= 0.46).

Sixty–eight percent (n=205) of the Dutch nephrologists were working in a district hospital, 85 of the 205 nephrologists participated in the survey. This was a response rate of 41.5%. A total of 97 nephrologist (32.1%) were working in a tertiary referral/university hospital. The response rate of this group was 24.7% (n=24).There was a significantly higher response rate in district hospitals compared to tertiary referral/university hospitals (41.5% vs 24.7%; p = 0.05). Table 1 illustrates the personal and practice characteristics of the respondents.

Table 1. Respondent characteristics (n=113)

	n (%)
Sex	
Male	70 (61.9)
Female	43 (38.1)
Age (years)	113 (100)
Median 47 (range 33-62)	
Mean 47.2 (SD 8.3)	
Position	
Nephrologist	111 (98.2)
Resident	2 (1.8)
Time of practice in nephrology	
0-11 month	1 (0.9)
1-2 years	2 (1.8)
3-5 years	13 (11.5)
6-10 years	28 (24.8)
11-15 years	19 (16.8)
15 years or more	50 (44.2)
Type of clinic/practice*	
Tertiary referral hospital (or university hospital)	54 (47.8)
General teaching hospital	27 (23.9)
District general hospital	30 (26.5)
Tertiary and district general hospital	1 (0.9)
Dialysis clinic, outside the hospital	6 (5.3)

* n differs due to multiple answers that could be given to this question
* Sexual dysfunction
** In less than half of the cases contains the answers “never “ and “in less than half of the cases”
*** In half or more of the cases contains the answers “the half”, “more than the half of the cases” and “always

Discussing sexual dysfunction

The majority of the respondents stated they 'never/almost never' (57.7%, n=64) or in 'less than half of the cases' (38.7%, n= 43) discussed SD with their new patients. Only 1.8% of the nephrologists (n=2) responded that they discussed SD 'in half' of their new patients, another 1.8% (n=2) responded to discuss SD in 'more than half' of their new patients. Nephrologists' answers regarding the frequency of discussing SD in different stages of CKD and with different patient groups are listed in Table 2.

Respondents were asked to note which reasons retained them from discussing the issue of SD. Results are shown in Table 3**.**

The most important reason (70.8%) was that patients not expressed their concern regarding sexual dysfunction spontaneously. A total of 92.8% of the respondents (n=103) stated that in less than half of the cases the patients express their sexual concerns spontaneously, 7.2% (n=8) responded that more than a half of their patients expressed their concerns spontaneously.

When SD is discussed, the most common subjects in male patients are: erectile dysfunction (ED) (92.9%), decreased libido (80.5%) and side effects of medication (59.3%). In female patients decreased libido (77.0%), pain during intercourse (52.2%) and side effects of medication (44.2%) are the most discussed subjects. 82.4% of the nephrologists (n =89) stated the partner to be present in "less than half of the cases" if SD was being discussed. Almost 18% (n=19) said the partner was present in "more than half of the cases".

All nephrologists were asked to note the importance of screening for SD in patients suffering from CKD. In 65.2% of the cases (n=73) nephrologists answered they think screening is 'slightly important', 24.1% (n= 27) stated 'important' and 0.9% (n=1) 'very important'.

A total of 9.8% (n= 11) answered they consider screening for SD 'unimportant' in patients suffering from CKD.

Table 2. Discussing SD* with different

How often do you discuss SD* with patients in:	**Less than half of the cases (%) ****	**In half of the cases (%)**	**More than half of the cases (%)*****
Stage 1: GFR > 90	109 (96.5)	3 (2.7)	1 (0.9)
Stage 2: GFR 60-89	110 (97.3)	2 (1.8)	1 (0.9)
Stage 3: GFR 30-59	106 (93.8)	6 (5.3)	1 (0.9)
Stage 4: GFR 15-29	99 (87.6)	6 (5.3)	8 (7.1)
Stage 5: GFR < 15	95 (84.1)	5 (4.4)	13 (11.5)
How often do you discuss SD* with patients in the following groups:	**Less than half of the cases (%) ****	**In half of the cases (%)**	**More than half of the cases (%)*****
Diabetic nephropathy	86 (76.1)	14 (12.4)	13 (11.5)
Chronic pyelonephritis	100 (88.5)	3 (2.7)	10 (8.8)
Alport syndrome	102 (90.3)	3 (2.7)	8 (7.1)
Receiving haemodialysis	87 (77.0)	8 (7.1)	18 (15.9)
Receiving peritoneal dialysis	86 (76.1)	8 (7.1)	19 (16.8)
After kidney transplantation	93 (82.3)	6 (5.3)	14 (12.4)
Other cause of chronic kidney failure	100 (88.5)	4 (3.5)	9 (8.0)

* Sexual dysfunction
** In less than half of the cases contains the answers “never “ and “in less than half of the cases”
*** In half or more of the cases contains the answers “the half”, “more than the half of the cases” and “always”

Table 3. Reasons that retain nephrologists from discussing SD*

Reason not to address SD*:	**Agree n (%)****	**Indecisive n (%)**	**Disagree n (%)*****
Patients do not express SD* spontaneously	80 (70.8)	20 (17.7)	13 (11.5)
Could not find a suitable moment	70 (61.9)	27 (23.9)	16 (14.2)
Insufficient time	53 (46.9)	26 (23.0)	34 (30.1)
High age of the patient	45 (39.8)	31 (27.4)	37 (32.7)
Age of the patient	35 (31.0)	33 (29.2)	45 (39.8)
Insufficient training	33 (29.2)	41 (36.3)	39 (34.5)
Barriers based on language or ethnicity	32 (28.3)	44 (38.9)	37 (32.7)
Barriers based on culture and religion	32 (28.3)	40 (35.4)	41 (36.3)
Insufficient knowledge	27 (23.9)	41 (36.3)	45 (39.8)
SD* isn't a problem for the patient	25 (22.1)	42 (37.2)	46 (40.7)
Patient is too ill to discuss SD*	25 (22.1)	38 (33.6)	50 (44.2)
Presence of a third person	20 (17.7)	34 (30.1)	59 (52.2)
I feel uncomfortable to talk about SD*	18 (15.9)	32 (28.3)	63 (55.8)
Sex is private	14 (12.4)	33 (29.2)	66 (58.4)
Afraid to offend the patient	12 (10.6)	25 (23.0)	75 (66.4)
Patient is not ready to discuss SD*	11 (9.7)	29 (2.7)	73 (64.6)
Sense of shame	11 (9.7)	25 (22.1)	77 (68.1)
No connection with the patient	11 (9.7)	23 (20.4)	79 (69.9)
Reason not to address SD*:	**Agree n (%)****	**Indecisive n (%)**	**Disagree n (%)*****
Someone else is accountable for discussing SD*	10 (8.8)	32 (28.3)	71 (62.8)
Patient is of the opposite sex	6 (5.3)	14 (12.4)	93 (82.3)
Age difference between yourself and the patient	5 (4.4)	21 (18.6)	87 (77.0)

* Sexual dysfunction
* *Agree contains the answers "totally agree" and " agree"
** *Disagree contains the answers "totally disagree" and "disagree"

Knowledge of sexual dysfunction

More than half of the respondents (58.0%, n=65) stated to have 'some' knowledge necessary to discuss issues concerning sexual function with patients, only 2.7% (n=3) stated to have 'a lot'. Over a quarter (34.8%, n=39) reported having 'not much' knowledge and 4.5% (n=5) had no knowledge at all to be able to discuss sexual issues.

A majority of the nephrologists (86.2%, n=94) stated that insufficient attention was paid to sexual dysfunction as well as treatment options during their residence training. Sixty-five percent of the respondents (n=73) stated to be in need of extending their knowledge on the discussing of SD.

Informing and counseling

Information was acquired regarding the managing of patients with SD problems. Nephrologists' answers regarding informing and counseling patients with SD are noted in Table 4**.**

Furthermore, respondents were asked on informing and counseling of patients with SD with regards to kidney transplantation. Results are listed in Table 5.

Table 4. Informing and counselling patients with sexual dysfunction

How often do you provide information regarding sexuality to:	**In less than half of the cases n (%)****	**In half or more of the cases n (%)*****
Male patients	108 (90.0)	12 (10.0)
Female patients	115 (95.0)	6 (5.0)
In how many cases do you:	**In less than half of the cases n (%)****	**In half or more of the cases n (%)*****
Subscribe PDE5 inhibitors to patients with ED*	73 (65.7)	38 (34.2)

* ED: erectile dysfunction

** In less than half of the cases contains the answers "never " and "in less than half of the cases"

*** In half or more of the cases contains the answers "the half", "more than the half of the cases" and "always"

Table 5. Informing & counselling around kidney transplantation

How often do you:	Never (%)	Seldom (%)	Frequently (%)	Often (%)	Always (%)	N* (Total)
Counsel patients on 'pregnancy after transplantation'	12 (10.9)	41 (37.3)	35 (31.8)	6 (5.5)	16 (14.5)	110
Tell about the diminishing of sexual dysfunction after kidney transplantation	24 (21.2)	50 (44.2)	33 (29.2)	4 (3.5)	0 (0.0)	113
Tell about the effect of immunosuppressant's on sexual function	31 (27.4)	63 (55.8)	12 (10.6)	3 (2.7)	2 (1.8)	113

*N differs because the questions were not answered consistently, some were skipped or forgotten

Accountability

Eighty percent of the nephrologists (n=90) noted no clear agreements have been made within their department regarding which care provider accounts for discussing patients' sexuality. Clear agreements were made in 14.3% (n=16), 5.4% of the responders (n=6) noted that they were unaware of an agreement.

Information was obtained regarding nephrologists' point of view as to which renal care provider is accountable for discussing SD. The results are illustrated in Figure 1.

According to nephrologists, an estimated 4.6% of the patients (±5.6 SD) were referred to another care provider for counseling of their sexual problems in the past year.

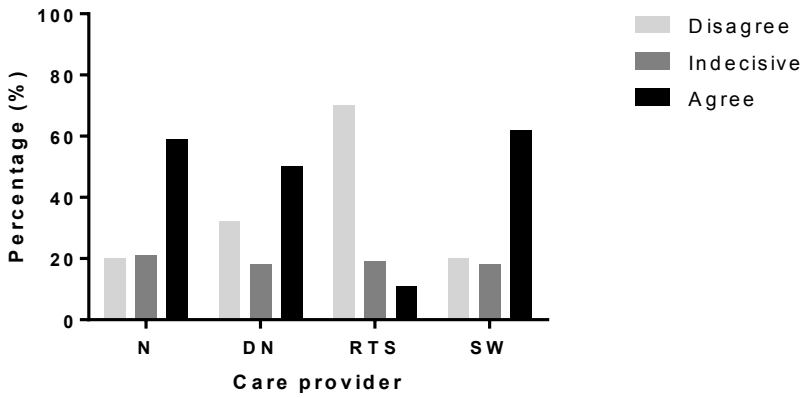

Figure 1. Accountability for discussing SD*
Abbreviations: N= nephrologist; DN= dialysis nurse; RTS= renal- and transplantation surgeon; SW= social worker
* sexual dysfunction
** Agree contains the answers "totally agree" and " agree"
*** Disagree contains the answers "totally disagree" and "disagree"

Discussion

The aim of this study was to determine to which extent nephrologists discuss the issue of SD with their patients suffering from CKD and the restraints towards discussing this subject. SD is a serious and common problem in patients suffering from CKD. No previous survey has been performed amongst nephrologists assessing their contribution towards the detection and counseling of SD. We obtained an insight into the nephrologists' general point of view, restraints towards discussing SD, general knowledge of this subject and need for training.

This study revealed that Dutch nephrologists rarely discuss SD. The main reason not to discuss SD is that patients do not express SD spontaneously. This point of view may cause an ongoing circle of avoidance. According to a US poll of 500 adults in the age group of 25 years and older, 71% of the interviewees were concerned about the fact that their doctor would dismiss any concerns regarding their sexual problems[25]. Speculating on this matter, the hesitation on both sides may be the reason talking about SD remains a problem amongst patients and nephrologists. Screening may be a solution to breaking through this ongoing circle of avoidance and detecting SD in an early stage. Given that only 24.1% of the nephrologist stated to find

screening for SD “important”, raising awareness on the importance of screening is indispensable. The importance of screening for SD in CKD has not yet been studied.
Time management also affects the frequency of discussion, as ‘insufficient time’ and ‘not finding a good moment to discuss’ were major reasons retaining nephrologists from discussing SD. Besides, ‘insufficient time’ was often a reason for nephrologists not to participate the survey. It implies time is a major constraint for nephrologists in the managing of SD.
To manage sexual health problems, adequate training is a requirement. In this survey 86% of the responders stated insufficient attention was paid to SD as well as treatment options during their residence training. The lack of education about SD is a widespread problem throughout all medical departments. There is no standardized training for medical students regarding sexual health and often students receive varied and sometimes even inadequate training[26,27]. The lack of training contributes to existing barriers, like insufficient knowledge and inadequate communication, when discussing SD[28]. Implementation of a sexual education program into residence training will contribute towards diminishing barriers regarding the discussing and counseling of SD. Rosen et al. 2005[29] pilot tested a workshop according to the ‘Robert Wood Johnson Model’. This study included residents from general medical specialist fields. Two-thirds (67.4%) of the participants noted they acquired a greater awareness of sexual problems because of the workshop. More than half of the participants (52.0%) stated the workshop made them more comfortable and skilled in the communication about sexuality with their patients[29]. For clinicians currently practicing, supplementary training should be provided by the National Federation of Nephrology in order to enhance their knowledge.
Sixty percent of the nephrologists stated that the accountability of discussing SD lies within their own group of professionals. These findings contradict the previous findings in a study from 2011 performed by Green et al. In this study 60% of a mixed group of renal care providers stated the primary accountability of managing SD lies with the primary care physician, only 35% stated it was the responsibility of the nephrologists[30]. Even though responders in this survey stated to be accountable for discussing SD, a majority (80%) stated no clear agreements were made within their department regarding which care provider has the accountability. To achieve real enhancement, clear agreements should be

made in co-operation with all care providers working in the nephrology department.
The results of this study suggest there might be a role for other renal care providers (e.g. dialysis nurse, social worker) in the discussing and detecting of SD. Patients with CKD are subject to a long-term follow up with several renal care providers; therefore an opportunity should be created to check-up with the sexual health of the patient. If there is a scheduled opportunity with a renal care provider specially trained in discussing sexual health, the issue of undervaluation of SD might be resolved. With regard to the management and counseling of SD, referral in early stage to an urologist, andrologist or sexologist may in the best interest for patients' health. These physicians are well trained in the counseling of sexual issues. This in contrary to other medical specialist whose education on SD in medical school as well during residence training is proven inadequate[26,27]. However, the sexual education of an urologist may be insufficient as well as a recent study showed the majority of the Dutch urology residents' (58.6%) stated they never received training or education on addressing sexuality[31]. No research is done on the level of sexual education in Europe during medical school or residence training in other medical departments.
More importantly, as the undervaluation of SD affects the patients with CKD and their partner[18], research should be performed towards their need for sexual counseling and the way this should be provided.
More research on the point of view of other renal care providers as well as patients and their partners might contribute to the development of an adequate method to enhance our current system.

Limitations
This study has a couple of limitations. Firstly, non-response bias may have occurred as a consequence of the low response rate and might have decreased the statistical power of the study. However, demographic characteristics have been compared between non-responder and responders. The self-reported character of the questionnaire may have caused social desirable answers. Also, it was not possible to obtain an insight in the residents' point of view on sexual health and communication skills during the current residence training. Residents were not reached as they are not members of Nefrovisie during their residency. However, no known attempts have been made to enhance sexual education during residence training in the past years. The study was performed using a non-

validated questionnaire. A validated questionnaire containing specific items on the discussing of SD with CKD patients does not exist. We decided not to validate the questionnaire as we did not intent to reuse the instrument. The structure and design of the used questionnaire were derived from questionnaires used in previous studies regarding sexuality and health care providers[20-24]. The usage of a non-validated questionnaire may have biased the answers of the respondents due to subjective questioning.

In perspective

This study contains evidential value for the operating principles of the Dutch nephrologists, however studies performed in the United States and Great Britain suggest the outcome of this study may be applicable in other Western countries[25,28,29]. Their results also showed omissions in discussing sexuality between doctors and patients, as well as a lack of education. Undoubtedly, patients' health status and kidney function take precedence above problems with their sexuality. The main focus should always be on treating the kidney disease and preserving kidney function. Nevertheless, effects of a decreased QoL due to SD on the course of CKD should not be underestimated. SD is a serious problem in all stages of CKD; predialysis, dialysis and after renal transplantation[8,32,33].
Besides, research has shown that a diminished QoL in patients receiving hemodialysis results in an increased risk of death and hospitalization[34].

Conclusion

In conclusion, Dutch nephrologists do not discuss problems with sexual function routinely. The lack of knowledge, suitable education and the lack of time are important factors causing undervaluation of SD in CKD patients. Implementation of sexual education into residence training and raising awareness among nephrologists on the importance of sexual dysfunction could improve care and quality of life for patients with CKD. More research should be performed among patients and other renal care providers to develop an adequate method to enhance our current system.

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