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

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4. Sexual care for patients receiving dialysis: a cross-sectional study identifying the role of nurses working in the dialysis department

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Introduction

According to WHO guidelines, sexual health is defined as "a state of physical, mental and social well-being in relation to sexuality" [1]. Unfortunately, sexual health is often diminished when suffering from a chronic illness, as a result of symptoms of disease and intensive treatments [2]. A familiar example is the deterioration of sexuality in patients who are dependent on dialysis treatment due to their renal disease [3,4]. For this reason, sexuality should be a subject regularly addressed in renal care [5].

Background

Sexual dysfunction (SD) is common throughout all stages of chronic kidney disease, however the prevalence reaches its summit when patients become dependent on dialysis; 70% of both male and female patients experience any form of SD [3,4,6-8]. Expression of SD in male patients includes erectile dysfunction, reduced libido and difficulty in reaching an orgasm [3]. Changes in body shape may play an important role as well since 30% of male patients on maintenance dialysis develop gynecomastia [4]. In women receiving dialysis, SD can manifest in reduced libido and lubrication, difficulty in achieving an orgasm and pain during intercourse [3,6,9]. The pathophysiology of SD in patients undergoing dialysis is often multifactorial and includes both organic and psychosocial elements [3,4]. Disturbances in the pituitary-gonadal axis, the uremic milieu and comorbid illness (e.g., neuropathy and vascular diseases) play an important role in the development of SD [3,4]. Psychosocial components include depression, anxiety and social withdrawal; all strongly associated with the presence of SD [10].
The impact associated with being dependent on dialysis treatment is not endured by patients alone, social and married life are affected as well [11]. Half of the partners from patients with a combination of dialysis treatment and SD experience decreased libido and sexual satisfaction themselves [11].

While literature describes the association of SD and dialysis, renal care providers are often unaware of patients' sexual issues [12]. Besides, adequate sexual care is often not provided and, if it is provided, little is known about the format and quality of this care [13]. To elucidate sexual care provided in the nephrology department, our research group composed multiple studies among renal care providers, including nephrologists, transplant surgeons and nephrology social workers [14,15]. These studies identified an absence of

guidelines regarding sexual care in most renal care departments [14,15]. Furthermore, the majority of renal care providers do not routinely discuss sexual problems with their patients [14,15]. For this reason, nurses of the dialysis department could make an important contribution to detecting and discussing SD in patients receiving dialysis [16-18]. Nurses are one of the most important contributors to a holistic approach of patients care, of which sexuality is an important component [16-18]. Especially in the dialysis department; nurses provide most of patients' daily care and they often have close contact with their patients due to intensive treatment sessions.

The study

Aims

The aim of this cross-sectional study was to explore to which extent Dutch nurses working with patients receiving dialysis discuss SD and to identify possible barriers restraining nurses from discussing SD. Furthermore, nurses' knowledge about SD was studied as well as the sexual education they received and nurses' opinion regarding the accountability for addressing sexual problems.

Participants

The study population consisted of Dutch nurses working with patients who receive dialysis, both in and outside the hospital. In the Netherlands, dialysis care is provided by both dialysis nurses and nurses specialized in nephrology; they received an additional 2 years of in-depth education about nephrology and dialysis. The nurses specialized in nephrology accounts for only a small percentage of all nurses in the dialysis department, so both types of nurses will be considered as one group. The inclusion criteria were: (i) age above 18 years; (ii) certified as a nurse and working with patients receiving dialysis treatment; (iii) able to complete a Dutch questionnaire. Nurses who did not meet all three inclusion criteria were excluded.

Design

This nurses-centred study used a cross-sectional explorative survey design.

Data collection

This research project was performed between January and May 2016 using a questionnaire. All Dutch dialysis centres (n=63), both in and outside

hospitals, received a request for participation, except for Leiden University Medical Centre since the pilot study was conducted in this centre. A total of 34 centres agreed on participation (54.0%); after agreement the estimated number of employees was asked per centre so the questionnaires could be sent without obtaining personal information. An estimated 1171 nurses have received their questionnaires at their work addresses. Non-responding centres received a reminder after 2 and/or 4 months after the initial mailing. An email was sent to participating departments 4 months after the initial mailing with the request to motivate their staff to complete the survey. An additional 40 questionnaires were handed out during a national meeting for nurses specialized in nephrology. In total, 1211 questionnaires were distributed among nurses working in the nephrology department.

Measurement

All authors contributed to the development and design of the 38-item questionnaire used in this survey. The structure was based on a literature search and previous questionnaires used in sexual health care studies [14,15,19]. A pilot test was performed by 23 nurses working in the nephrology department at the Leiden University Medical Centre to inspect the questionnaire for comprehensiveness, linguistics, content, layout and length. No comments were provided, therefore the final questionnaire was identical to the pilot questionnaire.

Both multiple-choice and open-end questions were used in the questionnaire and an opt-out option was offered to respondents on the first page. This page also contained questions focusing on gender, age, professional background and years of working experience. The subsequent questions focused on: (i) Nurses' practice patterns regarding enquiry and counseling patients undergoing dialysis about SD; (ii) Possible barriers that restrain nurses from assessing SD; (iii) Competence of nurses in discussing SD; (iv) Level of knowledge and training regarding SD in patients undergoing dialysis, including potential association with the provided sexual care; and (v) Nurses' perspectives about responsibility in addressing SD in renal care.

Ethical considerations

Informed consent was obtained from all nurses included in the study. In the Netherlands, this study does not fit the scope of the Medical Research

Involving Human Subjects Act (WMO) since no patients or interventions were involved; hence no ethical approval was required.

Data analysis

Data analysis was performed using IBM SPSS Statistics 23 (SPSS Inc., Chicago, IL, USA). Demographic data, as well as responses to the questionnaires, were described using frequency distributions. Observed frequencies were compared using the Pearson's chi-square test or the Cochran-Armitage Trend Test (Linear-by-Linear Association). The Spearman Rank Correlation Test was used to calculate a possible correlation between years of experience and frequency of discussion. To calculate a possible difference in the frequency of discussion with patients of different age groups, the age groups were divided into "≤65 years" and ">65 years". The answers "Never" and "Sometimes" were combined as well as the answers "Regularly" and "Often". Afterward, the McNemar test was used. Two-sided P-values <0.05 were considered statistically significant.

Validity, reliability and rigour

The study was performed using a non-validated questionnaire developed by the authors due to the non-existence of validated questionnaires exploring all study aims. Validation of this questionnaire has not been conducted since this specific questionnaire will not be reused. The authors attempted to develop reliable instrument by performing a pilot test and including literature and experience based questions.

Results

Participants

In total, 552 of the 1211 distributed questionnaires were returned, resulting in a response rate of 45.6%. Twenty-two respondents declined participation, reasons to decline included lack of interest (n=7), lack of time (n=4), improvement in this area is not possible (n=3) and lack of experience (n=2). Two questionnaires were excluded: one respondent completed less than 50% of the questionnaire and one respondent was not qualified as a nurse. With the inclusion of the pilot study (n=23), a total of 551 questionnaires were analyzed.

Demographics

Demographic and professional details of respondents are listed in Table 1. The majority of the respondents were female (n=495, 89.8%). Most

respondents were practicing as dialysis nurses (n=498, 90.4%), other positions were “nurses specialized in nephrology” (n=19, 3.4%), “dialysis nurses in training” (n=16, 2.9%) or “team leaders” (n=18, 3.4%).

Table 1. Characteristics of respondents (n=551)

	n (%)[a]
Gender	
Male	56 (10.2)
Female	495 (89.8)
Age	547 (99.3)
Median 47.0 (22-65 years)	
Position	
Dialysis nurses	498 (90.4)
Nurse currently in dialysis training	16 (2.9)
Team leader of dialysis department	18 (3.4)
Nurses specialized in nephrology	19 (3.4)
Other[b]	19 (3.4)
Dialysis experience	
0-11 months	13 (2.4)
1-2 years	24 (4.4)
3-5 years	66 (12.0)
6-10 years	136 (24.7)
11-15 years	107 (19.4)
>15 years	205 (37.2)
Employment setting	
University hospital	66 (12.0)
District general teaching hospital	217 (39.4)
District general hospital	184 (33.4)
University hospital and district general hospital	6 (1.1)
Dialysis clinic, outside the hospital	94 (17.1)
Other[c]	7 (1.3)

[a] n may differ due to multiple answers that could be given or questions that were skipped or forgotten
[b] include e.g. predialysis nurses, dialysis assistants, diabetic nurses and quality officers
[c] include e.g. home dialysis and combinations of dialysis clinics and unspecified hospitals.

Discussing SD

Several questions were addressed regarding how often nurses discussed SD with their patients (See Table 2). Of all respondents, almost a quarter (n=134, 24.5%) stated they discussed sexuality with 50% or more of their new patients. During follow-up, this percentage was lower: 13.5% (n=72).

If SD was discussed, 82.7% of nurses (n=430) reported that they never did so in the presence of the partner. No association was found between years of experience and frequency of discussing SD with new patients (Linear-by-Linear Association, p=0.09) or during follow-up (Linear-by-Linear Association, p=0.30). The Spearman Rank Correlation Test described also little correlation between experience and level of discussion with new patients (ρ=0.04) or level of discussion during follow-up (ρ=0.03).
Table 3 lists frequencies of talking about SD in relation to patients' age and gender. Almost 16% of nurses (n=81) regularly discussed SD with patients in the cohorts 16 to 35 and 36 to 50 years old. In the cohorts 51 to 65 years and 66 to 75 years, SD was regularly discussed by respectively 11.8% (n=62) and 5.9% of nurses (n=31). Four percent of nurses (n=21) discussed SD regularly with patients who reached the age of 76. Nurses discussed sexuality less often with patients above the age of 65 (McNemar test, p<0.001). No statistical differences were found in the frequency of discussing SD between male and female patients.
When asked how often patients expressed SD spontaneously, 39.1% of nurses (n=214) stated "never" and 56% (n=307) "in less than half of the cases". Other responses were "in half of the cases" (n=12, 2.2%), "more than half of the cases" (n=14, 2.6%) and "always" (n=1, 0.2%).

Table 2. Nurses' practice patterns regarding the discussion of sexual dysfunction

How often do you discuss sexual dysfunction?	Never n (%)	< 50% of the cases n (%)	50% of the cases n (%)	> 50% of the cases n (%)	Always n (%)
With new patients	159 (29.1)	254 (46.4)	50 (9.1)	43 (7.9)	41 (7.5)
During follow up	207 (38.7)	256 (47.9)	34 (6.4)	21 (3.9)	17 (3.2)
In presence of the partner	430 (82.7)	64 (12.3)	17 (3.3)	6 (1.2)	3 (0.6)

Note: n differs because the questions were not answered consistently, some were skipped or forgotten

Table 3. Discussing sexual dysfunction in relation to patients' gender and age

	Never n (%)	Sometimes n (%)	Regularly n (%)	Often n (%)
Patients' gender				
Male	145 (26.8)	311 (57.4)	72 (13.3)	14 (2.5)
Female	161 (29.8)	290 (53.7)	73 (13.5)	16 (3.0)
Patients' age				
16-35yr	142 (27.1)	268 (51.1)	81 (15.5)	33 (6.3)
36-50yr	133 (25.1)	288 (54.3)	81 (15.3)	28 (5.3)
51-65yr	186 (35.4)	260 (49.5)	62 (11.8)	17 (3.2)
66-75yr	274 (52.5)	206 (39.5)	31 (5.9)	11 (2.1)
≥76yr	363 (69.4)	130 (24.9)	21 (4.0)	9 (1.7)

Note: n differs because the questions were not answered consistently, some were skipped or forgotten

Barriers

Respondents received a list of possible barriers that could restrain them from discussing sexuality. They were asked to which extent they agreed or disagreed with these barriers (See Table 4). The most important barrier to not discuss sexual health was based on "language and ethnicity" (n=310, 57.3%), followed by "religion and culture" (n=296, 54.1%) and "an older age of the patient" (n=271, 49.7%). Barriers least agreed on by respondents were "no possibility to refer the patient" (n=357, 65.6%), "insufficient time" (n=366, 67.2%) and "the patient is of the opposite sex" (n=373, 68.1%).

Knowledge and training

Nurses rated their own level of knowledge on SD in patients receiving dialysis. Eighteen percent (n=99) considered their knowledge to discuss SD as sufficient, whereas 42.4% (n=233) thought to have "some" knowledge on this subject. Over 200 nurses (n=203, 37.0%) rated their level of knowledge as "little" and 2.6% (n=14) said to have no knowledge about SD at all. Regarding nurses' competence to discuss SD, 51.2% (n=275) felt competent to discuss SD with their patients. Almost 70% of nurses (n=370, 68.3%) declared to be in need of improving their knowledge on sexuality to discuss this subject. Nurses with more knowledge on SD and/or those who felt competent discussed SD more often with new patients and during follow-up (Linear-by-Linear Association, $p<0.001$ for all associations). Three-quarter of nurses (n=409,

75.5%) received education regarding sexuality in patients undergoing dialysis treatment as part of their training to become a dialysis nurse.

Table 4. Barriers towards discussing sexual dysfunction

Reasons not to address SD[a]	Agree n (%)[b]	Indecisive n (%)	Disagree n (%)[c]
Language and ethnicity	310 (57.3)	156 (28.8)	75 (13.9)
Religion and culture	296 (54.1)	172 (31.4)	79 (14.4)
High age of the patient	271 (49.7)	128 (23.5)	146 (26.8)
Patients do not express SD[a] spontaneously	266 (48.8)	145(26.6)	134 (24.6)
Could not find a suitable moment	262 (48.5)	145 (26.9)	133 (24.6)
Presence of a third person	252 (46.4)	137 (25.2)	154 (28.4)
Age of the patient	243 (44.4)	160 (29.3)	144 (26.3)
Insufficient training	230 (42.5)	167 (30.9)	144 (26.6)
I feel uncomfortable to talk about SD[a]	173 (31.8)	191 (35.1)	180 (33.1)
Sex is private	160 (29.4)	241 (44.2)	144 (26.4)
No connection with the patient	154 (28.2)	145 (26.6)	247 (45.2)
Patient is too ill to discuss SD[a]	152 (27.9)	220 (40.4)	173 (31.7)
Age difference between yourself and the patient	132 (24.2)	127 (23.3)	287 (52.6)
Sense of shame	131 (24.1)	195 (35.9)	217 (40.0)
Insufficient knowledge	121 (22.2)	184 (33.8)	240 (44.0)
Afraid to offend the patient	113 (20.9)	159 (29.4)	269 (49.7)
Patient is not ready to discuss SD[a]	112 (20.8)	247 (45.8)	180 (33.4)
SD[a] is not a problem for the patient	72 (13.2)	227 (41.6)	247 (45.2)
Patient is of the opposite sex	60 (10.9)	115 (21.0)	373 (68.1)
No possibility to refer the patient	58 (10.7)	129 (23.7)	357 (65.6)
Someone else is accountable for discussing SD[a]	58 (10.6)	151 (27.6)	338 (61.8)
Insufficient time	54 (9.9)	125 (22.9)	366 (67.2)

Note: n differs because the questions were not answered consistently; some were skipped or forgotten
[s] SD: sexual dysfunction
[b] Agree contains the answers "totally agree" and "agree".
[c] Disagree contains the answers "totally disagree" and "disagree"

After nurses finished their training, the majority "never" (n=197, 36.2%) or "rarely" (n=309, 56.8%) received education regarding sexuality during in-service training again. Seven percent (n=37, 6.8%) stated that this subject was "regularly" discussed during in-service training; one respondent (n=1, 0.2%) reported that SD was "always" discussed.

Accountability

One item in the questionnaire inquired after nurses' opinion regarding which renal care provider should be accountable for the discussion of SD with patients receiving dialysis (Figure 1). Most of the respondents (n=448, 82.8%) thought the nephrologist should be accountable for discussing SD, whereas 66.8% (n=362) held the social worker accountable. Almost an equal percentage (n=360, 66.3%) stated that this accountability should lie in their own group of professionals. The transplant surgeon was mentioned by 43.5% (n=236) of the respondents.

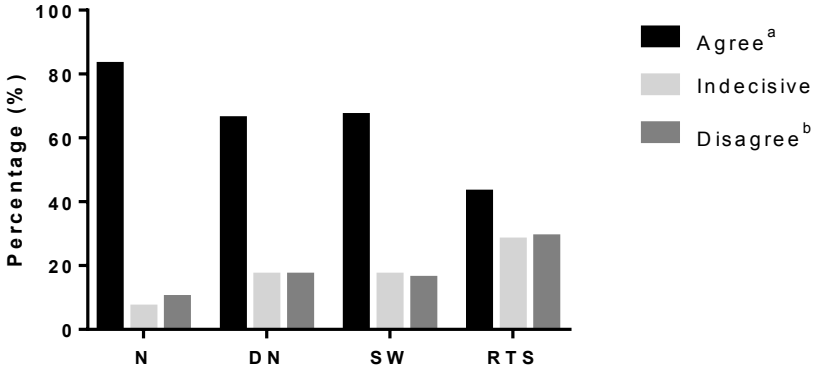

Figure 1. Which renal care provider should be accountable for the discussion of sexual dysfunction?
Abbreviations: N= nephrologist; DN= dialysis nurse and nurse specialized in nephrology; SW= social worker; RTS= renal and transplantation surgeon
[a] Agree contains the answers "totally agree" and "agree"
[b] Disagree contains the answers "totally disagree" and "disagree"

Organization

The survey assessed if general guidelines were present in nurses' centres that impose the discussion of sexuality with patients receiving dialysis treatment by renal care providers. Almost 44% of the respondents (n=234, 43.3%) were aware of such guidelines, 35.8% (n=193) had no guidelines imposing the discussion of sexuality and 20.8% (n=112) were unaware of such guidelines. When asking if clear agreements were present which appoint the accountability of discussing sexuality to a specific renal care provider, 37.5% of nurses (n=204) were aware of those agreements in their centre. In 69.6% (n=142) of these agreements, the nurses were held accountable. Other given answers were, for example, a combination between nurse and nephrologist (n=22, 10.8%), the nephrologist (n=6,

2.9%) or the social worker (n=5, 2.5%). Nurses who were aware of guidelines in their centres imposing renal care providers as accountable for discussing SD in patients undergoing dialysis discussed SD more often with new patients and during follow-up (Linear-by-Linear Association, $p<0.001$ for all associations).
When focusing on how often patients receiving dialysis were referred for counseling to care providers specialized in SD, an average of 1.16% of patients was referred by the nurses.

Facilitation
The questionnaire focused also on items that could facilitate nurses to discuss SD with their patients. On the question "Is sufficient information regarding sexuality available at your department to hand out to patients?" 92 nurses (17.5%) answered confirmative.
In addition, a list of possible tools to enable nurses to discuss SD was included. Information brochures (n=462, 83.8%) and training in discussing sexuality (n=296, 53.7%) were frequently mentioned options. Other suggestions were "the possibility to refer to a sexologist" (n=241, 43.7%), "the nephrologist should discuss this subject, so I could refer to this conversation" (n=196, 35.6%) and "posters in the waiting room" (n=92, 16.7%). A self-reported open answer given by several nurses on the question "What could help you to discuss SD?" was "more privacy" (n=34, 6.2%).

Discussion
This study is one of the first to identify that nurses working in the dialysis department do not routinely discuss SD with their patients. Regardless of nurses' experience or patients' gender, nurses often leave out the inquiring about patients' sexuality during consultation. These findings are similar to those of Ho 2006, which studied care for sexual health among Spanish nurses in the nephrology department. Inquiry about patients' sexuality was often forgotten during consultation as nurses felt embarrassed to address this subject or were restrained by their conservative attitude [20]. The present study found that a considerable part of Dutch nurses feel responsible for discussing SD and have the time to do so, however they are often hold back by patients' old age. Although literature suggests that sexuality could still be important for elderly people [21]. In addition, about half of the nurses are restrained from discussing SD by barriers based on language and ethnicity or religion and culture. These barriers might be explained in the

light of the increasing cultural diversity among patients and care providers [22-24]. In the past years, competencies that enable care providers to provide health care to patients of diverse ethnicities have become more important [22-24]. Especially when this includes the discussion of difficult and sensitive topics, such as sexuality. Cultural challenges in providing sexual care are not limited to nurses in the nephrology department; they are experienced throughout other medical departments as well [20,23,24]. The current situation might benefit from additional training for nurses to improve their knowledge and competence regarding the provision of health care in the context of cultural diversity.

Knowledge and competence regarding sexuality in times of dialysis are important elements of nurses' practice patterns in providing sexual care as well. Unfortunately, this study identified that some nurses find their knowledge and competence low and most of them feel in need of training regarding sexual health. However, when focusing on perceived barriers, not all responding nurses are aware of the influence knowledge has on their practice patterns regarding care for sexual health. The lack of knowledge and awareness is most likely a result of insufficiency in the current educational system; an omission recognized by nurses both nationally and internationally [20,25]. Present findings, endorsed by literature, emphasize the necessity of implementing adequate education and training for nurses to incorporate sexual care into daily practice [16,26,27]. However, little is known about the long-term effectiveness of the implementation of sexual education and training and if the renewed skills and practice patterns will sustain over time [27]. Jonsdottir et al. 2016 implicated that besides implementation of education and training, more structural adjustments are necessary to facilitate actual improvement [28]. Even though this study was performed among oncology care providers, these implications might also be applicable to dialysis department since similar situations are present in more medical departments [19,29].

When focusing on these structural adjustments, the study outcomes underline the need for improvement on an organizational level. Currently, there appears to be an absence of information available when it comes to sexual health in dialysis departments. The vast majority of nurses stated that information brochures to hand out to patients and partners would be a helpful tool to enhance the conversation about SD. Another self-reported tool on organizational level would be the facilitation of more privacy for a consultation about sexual health. Nurses in the nephrology department often see their patients in crowded hemodialysis units.

Facilitation of a scheduled and private conversation to inquire after patients' sexuality may be an important first step for a consultation about sexual health to take place between patient and nurse. Especially, since time was not a constraint for nurses to discuss sexuality, only finding a suitable moment was.
Simultaneously to these organizational improvements, guidelines that impose sexual care for patients receiving dialysis facilitate the foundation for this part of renal care. Currently, according to a majority of renal care providers, no such guidelines are present in their departments [14,15]. In addition, these guidelines should indicate which renal care providers are accountable for this part of care. Most preferable is a shared accountability for all care providers; each care provider could make a contribution that is suitable for their daily practice [14,15]. For example, the nephrologist could have the primary responsibility and initiate the subject sexuality during consultation [14]. This could enable nurses and social workers to discuss this subject more extensive during their consultation. In addition, the transplantation surgeon could briefly mention that receiving a kidney transplant could improve SD, however the persistence of SD after transplantation is not uncommon. This information could prepare patients so hopefully unfulfilled expectations after transplantation will be prevented [15].
Nevertheless, it is important not to underestimate the difficulties of providing extensive sexual care for patients. Even though renal care providers are able to address and discuss sexuality with their patients, patients should be referred for more specialized sexual care if SD is a problem imposing patients' well-being. Currently, only 1% of patients are referred by the nurse to a care provider specialized in sexual issues. The hypothesis underlying to this low number of referral is that this may be a result of the absence of clear referral options. Although most nurses were not restrained by this absence when discussing SD, they thought it would be helpful if this possibility to refer patients to specialized care provider was present.

Strengths and limitations
This study was one of the first to explore the perspective of dialysis nurses and nurses specialized in nephrology on sexual care for patients receiving dialysis treatment. This strength also creates a limitation since formal comparison with other literature is limited.
Response bias may have occurred in this study since some Dutch dialysis

centres declined participation and the response was not complete. Besides, the response rate might have been influenced by an over-or underestimation of the number of employees per centre or due to questionnaires not being distributed equally among all employees. In addition, this survey was conducted using a non-validated questionnaire developed by the authors. However, no validated questionnaire exists that assessed all aims of the study. Furthermore, over- or underestimation may have occurred as a result of a social desirability bias.

Conclusion

Nurses of the dialysis department do not regularly address the subject sexuality in conversations with their patients, especially those being of older age. Although nurses feel responsible to do so, they are restrained from discussing this important subject by self-reported insufficient knowledge, competence and training and challenges that arise from cultural diversity among patients and care providers. According to the study outcomes, these obstacles could be overcome by adjustments in the current educational system. However, the main challenges that underlie current hurdles in providing sexual care for patients undergoing dialysis derive from organizational problems such as the absence of guidelines and privacy in treatment facilities. Results of the present study emphasize the need for a multidisciplinary approach to sexual care with clear guidelines throughout all nephrology departments, awareness among renal care providers, facilitation of a suitable moment to discuss SD and adequate referral systems to a physician specialized in SD.

Research should be performed among patients receiving dialysis and their partners to determine their needs and perspectives regarding sexual care in nephrology.

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