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

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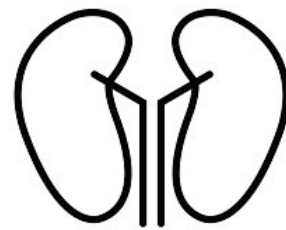
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## **Part II**

### **Sexual care, relationships & chronic kidney disease**

#### **The perspective of patients and their partners**

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## ***6. Exploring sexual care in end-stage renal disease in the Netherlands: a pilot study from the perspective of patients and partners***

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## **Introduction**

The prevalence of patients suffering from end-stage renal disease is increasing worldwide due to aging of the population and an increase in the prevalence of diabetes (1, 2). The course of renal disease is characterized by two phases of major impact 1) when patients become dependent dialysis and, 2) when they are found eligible to receive a kidney transplant.

Although physiology and psychology difference largely between patients of the two different phases, they often have one thing in common: up to 70% of men and women experience sexual dysfunction (SD) (3-7).

The dialysis phase is associated with disturbances in the pituitary-gonadal axis, uremia, and psychosocial distress (3-6). In turn, these disturbances can negatively affect sexual function. SD in men is manifested as erectile dysfunction, reduced libido, and difficulty in achieving orgasm (4, 5, 8).

About 30% of men receiving dialysis also develop gynecomastia; a symptom that could have a deteriorating impact on self-image, indirectly influencing male sexuality (7). In women, SD is often expressed by decreased libido and vaginal lubrication, pain during intercourse, and difficulties in achieving an orgasm (4, 9). These effects on sexual health are not only limited to patients, approximately 50% of partners experience SD as well when confronted with end-stage renal disease (10).

When patients are found eligible for renal transplantation (RTx), many things change and most will experience an enhancement in overall well-being. Yet, up to 60% of male and female transplant recipients still report SD (11-13). Some dysfunctions arise from patients' anxiety to harm the transplanted kidney during intercourse, or from the use of immunosuppressive medication (14-16). This endurance of SD after RTx could result in a decrease in patients' life satisfaction and well-being (17, 18).

In sum, SD could be an evident problem during dialysis as well as after RTx for both patients and partners. Therefore, it is important that, at a certain point in the course of the disease, information about sexual function is provided. Some information about sexuality is available through the Dutch Kidney Foundation, Dutch Association of Kidney Patients or at the hospital. Yet, it is unknown on whether patients and partners receive this information or when they prefer to receive it: during dialysis, after renal transplantation or both. Besides, inquiring about sexual health is not a standard component of the current health system. The main renal care providers, including nephrologists, transplant surgeons, nurses of the dialysis department, and social workers, do not routinely discuss these

topics with their patients before or after RTx (19-21). Self-reported reasons not to discuss sexual health include insufficient knowledge, a lack of suitable moments to address this subject, and cultural diversity among patients and care providers (19-21). If sexuality is addressed in renal care, it is focused on patients' sexuality. Partners are often not involved (19-21). Therefore, in addition to the evaluation among renal care providers, this cross-sectional pilot study is the first to focus on patients and partners' needs, perspectives and preferences regarding sexual information and sexual care during dialysis or after RTx. Information was obtained about the preferable timing of this part of care: during dialysis or after RTx.

## **Materials and methods**

### *Participants*

Data were collected between July 2016 and July 2017 among patients (and partners) in two phases of renal disease: during dialysis and after RTx. Patients undergoing dialysis, including hemodialysis and peritoneal dialysis, and their partners were included from one tertiary dialysis facility (Leiden University Medical Centre (LUMC), n=73) and two secondary dialysis facilities: Haga Hospital (Haga), n= 108) and Haaglanden Medical Centre (HMC), n=139).

The study population focusing on renal transplantation consisted of all patients that underwent a kidney or kidney-pancreas transplantation in the LUMC between July 2014 and July 2016 (n=257). Their partners, if applicable, were evaluated as well.

To be included patients and partners needed to be 18 years or older, and had to be able to fully understand and complete questionnaires in Dutch or English.

### *Procedure*

Invitations to participate in the studies were distributed by mail or in person. When patients were invited by mail, they received an information letter and informed consent form at their home address. In the same envelope, a separate information letter and informed consent form for their partners were added. After consent was obtained, the questionnaire was sent; separately dispatched for patients and partners. If patients were invited in person, they received an envelope, including information letters

and informed consent forms for patient and partner, from a nephrologists or nurse during the morning round. The questionnaires were sent by mail after consent was provided. Patients and partners that indicated to participate but did not return the questionnaire were reminded after four, eight and/or sixteen weeks.

#### *Privacy of participants*

In order to secure privacy, all participants received an identification code. The documents containing personal information were locked using a password. All questionnaires were processed and analyzed anonymously.

#### *Instruments*

In total, four different instruments were used to conduct this study; two questionnaires designed to evaluate patients' perspective (dialysis or RTx orientated), the other two to evaluate the perspective of the partner (dialysis or RTx orientated). The questionnaires were developed by the authors, based on extensively tested questionnaires used in previous research performed by our research group (20). The patients' questionnaire comprised 41 items in the dialysis group and 53 items in RTx group. The questionnaires used for partners in the dialysis and in the RTx phase both comprised 37 items. All contained multiple-choice questions, open-ended questions as well as a scale question to rate possible impact on well-being on a 1 to 10 scale (1, no impact and 10, severe impact). The questionnaires were pilot-tested by trained members of the Dutch Association of Kidney Patients (NVN).

Questionnaires contained items assessing the following data: 1. demographic characteristics and disease specifications; 2. presence and impact of sexual dysfunction; 3. current sexual care provided by renal care providers; 4. needs and perspectives regarding sexual care; 5. preferred timing of sexual care. In addition, all questionnaires contained questions on the impact of disease and treatment on the relationship between patient and partner, those questions were analysed and described separately.

#### *Ethical consideration*

The study was approved by the local ethical committee of the Leiden University Medical Centre (LUMC) and performed according to the guidelines of the Medical Research Involving Human Subjects Act (WMO). Personal data were handled according to the Dutch law (Personal



Data Protection Act). All the participating patients and partners signed a written informed consent.

### *Statistical analysis*

After the questionnaires were returned, all data were analyzed using IBM SPSS Statistics 23 (SPSS Inc., Chicago, IL, USA). Both demographic information and responses to the questionnaires were analyzed using frequency distribution. Shapiro-Wilk tests were used to test if age, relation duration, and the rated impact of SD were normally distributed. The Pearson chi-square test was used to compare the self-reported sexual activity of patients in the dialysis group before and after starting with dialysis. To compare age between the participants of the dialysis and the transplantation group, the independent T-test. The Mann-Whitney test compared the effect of gender and different phase of disease on the experienced impact of SD on well-being. Outcomes were considered statistically significant if the *P* value was < 0.05.

## **Results**

### *Survey responses*

In the dialysis group (n=320), 30 patients (9.0%) and 9 of their partners were willing to participate. In the RTx group (n=257), 37 renal transplant recipients (14.4%) and 19 of their partners participated. Two patients in the dialysis group and one transplant recipient were excluded because less than 50% of their questionnaire was completed. Of the dialysis group, 28 patient questionnaires and 9 partner questionnaires were analyzed. Of the RTx group, questionnaires of 36 patients and 19 partners were analyzed.

### *Characteristics*

The majority of respondents were male; 67.0% in the dialysis and 69.4% in the RTx group respectively. Participants receiving dialysis ( $68.3 \pm 14.8$ ) were older than those in the RTx group ( $58.3 \pm 10.6$ ;  $p < 0.001$ ). In the dialysis group, most respondents received hemodialysis (n=23, 82.2%). Six of them (22.2%) received peritoneal dialysis and one nocturnal dialysis at home (3.7%). A quarter of patients receiving dialysis (n=7) had received a renal transplant before. In the RTx group, the majority of the transplant recipients (n=31, 86.1%) received a transplant for the first time. All of them received the transplant more than 1 year ago. More characteristics, including demographics, of patients and partners are shown in Table 1.

**Table 1.** Demographics of patients and partners

	Dialysis		Renal transplantation	
	Patients (n=28)	Partners (n=9)	Patients (n=36)	Partners (n=19)
Gender n (%)				
Male	19 (67.9)	2 (22.2)	25 (69.4)	7 (36.8)
Female	9 (32.1)	7 (77.8)	11 (30.6)	12 (63.2)
Age				
Mean age in years (SD)	68.9 (14.8)	66.6 (15.8)	58.7(10.6)	57.5 (10.7)
Relationship status n (%)				
Single	10 (35.7)		6 (16.7)	
In a relationship	2 (7.1)		7 (19.4)	
Married	8 (28.6)		20 (55.6)	
Widowed	7 (25.0)		2 (5.6)	
Divorced	1 (3.6)		1 (2.8)	
Relationship duration				
Mean duration in years (SD)	45.4 (13.1)		27.0 (14.4)	
Level of education n (%)				
None - primary or basic	2 (7.1)	2 (22.2)	4 (11.1)	1 (5.3)
Lower general secondary Education	5 (17.9)	1 (11.1)	5 (13.9)	6 (31.6)
Intermediate Vocational Education	2 (7.1)	1 (11.1)	9 (25.0)	5 (26.3)
Higher general Education	2 (7.1)	0 (0.0)	1 (2.8)	0 (0.0)

Pre-university Education	0 (0.0)	0 (0.0)	0 (0.0)	1 (5.3)
Higher Vocational Education or Academic	14 (50.0)	4 (44.4)	17 (47.2)	6 (31.6)
Employment status n (%)				
Working	1 (3.6)	3 (33.3)	9 (25.0)	11 (57.9)
Not able to work because of disease	5 (17.9)	1 (11.1)	9 (25.0)	1 (5.3)
Retired	20 (71.4)	5 (55.6)	13 (36.1)	4 (21.1)
Other <sup>a</sup>	2 (7.2)	1 (11.1)	5 (13.9)	3 (15.8)
Duration of disease				
0-5 years	12 (42.9)		7 (20.6)	
5-10 years	7 (25.0)		11 (32.4)	
10-15 years	4 (14.3)		7 (20.6)	
>15 years	5 (17.9)		9 (26.5)	

Note: n may differ due to some questions that were skipped or forgotten  
<sup>a</sup>including e.g. searching for work, student, and volunteer

### *Sexuality during dialysis and after RTx*

Almost 60% of the patients receiving dialysis reported they were sexually active before they started with dialysis. A significantly lower percentage of patients (25.9%,  $p=0.04$ ) reported still being sexual active after starting dialysis. About 35.7% experienced SD after starting dialysis, problems mentioned were erectile dysfunction (30.8%) and lack of libido (15.4%). Among renal transplant recipients, 50% experienced SD before they received the transplant. More specifically, they had erectile dysfunction (36.8%) and difficulty achieving orgasm (36.8%). In addition, patients receiving dialysis, as well as the RTx group mentioned “fatigue” as an additional factor that stopped them from being sexually active (in 19.2% resp. 42.1%). Transplant recipients were asked if the sexual complaints changed after RTx. More than a fifth (21.2%) of patients stated the

complaints remained the same, 15.2% indicated the complaints decreased and 9.1% mentioned an increase of sexual complaints. Nine percent did not experience SD before RTx, hence developed sexual problems afterward. Two patients of the dialysis group (7.1%) and the RTx group (5.7%) were referred for counseling with a professional specialized in SD. Focussing on the self-reported impact of SD on well-being, patients undergoing dialysis and their partners scored this impact as 3.5 (Range 0-10) and 2.0 (Range 0-10). In the RTx group, the impact was rated with a median of 5.0 (Range 0-10) by patients and 3.5 (Range 0-10) by partners. No significant difference in self-reported impact was observed between the dialysis and the Rtx group ( $p=0.558$ ), between male and female patients ( $p=0.11$ ), or between male and female partners ( $p=0.613$ ).

#### *Information about sexual health in renal disease*

In the dialysis group, 85.7% of patients and all partners indicated they never received information about the effect of dialysis on sexuality. Among renal transplant recipients, 77.0% of patients and 84.2% of partners were also never informed of the effect of RTx. If patients undergoing dialysis or renal transplant recipients received information, this was provided during consultation with their renal care provider (resp. 17.9 and 30.0%) or in a brochure (resp. 10.7 and 30.0%). A quarter of patients receiving dialysis and a third of their partners stated they would like to receive information about sexuality. In the RTx group, these percentages were higher; 76.5% of patients and 57.9% of partners preferred information. Table 2 shows the preferred formats to receive information as indicated by respondents that noted more information was necessary. Both in the dialysis and RTx group, patients and partners preferred to receive information about sexuality during consultation with a renal care provider (percentages ranging from 54.6 up to 85.7%).

#### *Consultation about sexuality*

Patients were asked who should initiate the conversation about sexuality. A third of the patients receiving dialysis thought the nephrologist should, 31.4% of transplant recipients pointed to the nephrologist as well. Some patients indicated that it should be their own responsibility to bring up the topic sexuality (16.7% in the dialysis group; 45.7% in the RTx group).

**Table 2.** Receiving information about sexuality

	Dialysis		Renal transplantation	
	Patient n (%) <sup>a</sup>	Partner n (%) <sup>a</sup>	Patient n (%) <sup>a</sup>	Partner n (%) <sup>a</sup>
<b>How would you like to receive information about sexuality?</b>				
Conversation with a renal care provider <sup>b</sup>	6 (85.7)	2 (66.7)	20 (76.9)	6 (54.6)
Conversation with a sexologist or psychologist	1 (14.3)	2 (66.7)	14 (53.8)	4 (36.4)
Informative brochure	3 (42.9)	2 (66.7)	6 (23.1)	4 (36.4)
Website	2 (28.6)	0 (0.0)	4 (15.4)	2 (18.2)
Electronic application	2 (28.6)	1 (33.3)	1 (3.8)	1 (9.1)

*Note: n may differ due to multiple answers that could be given and because some questions were skipped or forgotten*

<sup>a</sup> Percentages of the participants who indicated they would like to receive information

<sup>b</sup> contains the answers “physician” and “nurses and social workers”

Main reasons not to initiate a conversation about SD for patients receiving dialysis were: ‘it has no priority’ (28.6%), ‘I do not have a partner’ (28.6%), and ‘sex is private’ (17.9%). Likewise, 21.2% of the transplant recipients indicated a conversation about SD was no priority, others would rather discuss this with their partner (21.2%).

Both during dialysis and after RTx, more than the half of patients (resp. 57.1 and 78.0%) thought that a scheduled consultation to be informed about sexuality should be offered to every patient. In the dialysis group, one-third of the partners thought it would be important to be present during this consult. Of the partners in the RTx group, 66.7% indicated it to be important to be present during that consult.

## Discussion

This pilot study is one of the first to address care for sexual health from the perspectives of both patients and partners in two phases of end-stage renal disease: during dialysis and after RTx. Although current outcomes should be considered explorative, an impression is provided of current sexual care in nephrology. Due to the main outcomes set forth by this study the question arises if sufficient information about sexuality is provided to patients and partners confronted with dialysis and RTx. These findings are endorsed by Muehrer et al. (22) in a study among renal transplant recipients in 2014. Muehrer and colleagues found that 40% did not receive information about sexuality and more than a quarter was concerned about the communication with their renal care provider regarding this subject (22). Yet, present study indicates that among patients receiving dialysis and their partners just a small percentage is in need of receiving information about sexual health. This low percentage among patient might be explained by the fact that few participants were in a relationship or marriage. Another explanation could be that due to the intensive treatment sessions and a lingering illness sexuality could become less of a priority. For example, Mor et al. (23) showed that although low sexual activity was reported among female patients receiving dialysis, only a small group perceived this as problematic and 5% was eager to be informed about possible underlying causes or treatment options (23). This might not apply to all, however, since even in the end-stage of disease or in a palliative setting sexuality could be still of importance (24). Transplant recipients and their partners seem more interested in receiving information about sexuality, most preferable during consultation with a care provider and in the presence of their partner. Since all participants were at least one year after their renal transplantation, timing of this consultation might be best around this time. The initiation of this consultation should probably come from the renal care provider. Although some renal transplant recipients acknowledged their own responsibility in addressing sexuality, in general most patients are retained by feelings of shame or embarrassment (25, 26). A majority of renal care providers, however, experience several barriers themselves that retain them from inquiring about sexual health, including organizational and educational shortcomings (19-21). In order to implement care for sexuality in renal care successfully, these difficulties need to be overcome first (19-21).

### *Strength and limitations*

As this study was one of the first to evaluate care for sexual health from the perspectives of both patients and partners in two renal disease stages, comparison with literature was limited. Unfortunately, this pilot study was limited by a low response rate. A possible explanation for this can be found when focusing on the study population. As a lot of research is performed in the field of renal disease, patient (and partners) are too often approached with a request of participation. Second, patients with end-stage renal disease are confronted with periods of severe symptoms and sickness. As a result their focus might be more on survival than on contributing to scientific research or on sexuality in general. On the other hand, for those who received a kidney transplant and regained their health, participation in this study could be an unpleasant reminder of previous sickness. As a result of the low response rate, a non-responder and selection bias could have occurred. Response bias may also have occurred due to the self-reporting character of the study design. Furthermore, the questionnaires used in this study are not validated, however thoroughly criticized and pilot tested by physicians, patients, and partners.

### **In perspective**

Present findings appoint that information about sexuality during the course of end-stage renal disease is best provided around a year after renal transplantation. Nevertheless, it appears to be important for patients undergoing dialysis to be offered the opportunity to discuss their sexual health. It is essential to strive for a solution that fits the preferences of patients and partners and at the same time is practical and feasible for renal care providers. For example, time restraints are a major problem among nephrologists, so a scheduled consultation with a specialized nurse might be a good alternative (19-21). This group of care providers feels responsible for providing this part of care and additional training and privacy could enable them to do so (19). The time nurses have per patient is not unlimited either; therefore, another solution could be the development of supporting tools, such as informative videos or eHealth applications. Even for the elderly, this could be a welcome instrument enlarging their self-management abilities (27). In addition, focusing on easily accessible referral systems to specialized sexual care providers

might be beneficial for patients, partners, and renal care providers (19-21). Most important is to conduct more profound research on a larger scale, to be able to make final recommendations. Future projects should explore and determine precisely which improvements and tools would be beneficial to provide adequate sexual care in nephrology.

### **Conclusion**

Current pilot study findings imply that the provision of sexual care is not standard for patients and partners confronted with end-stage renal disease. Transplant recipients experience this as an unmet need, whereas patients undergoing dialysis and their partners appoint less importance to information about sexual dysfunction. It appears that future implementation of sexual care should focus on the transplantation phase. Yet, it is preferable to provide an opportunity to discuss sexual health during dialysis. Before structural and organizational adjustment can be made successfully, however, more profound research is necessary.



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